

**CHILD-PARENT SHIFTING AND SHARED DECISION-  
MAKING FOR ASTHMA MANAGEMENT**

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**Introduction**

Asthma is the most common long-term illness in children and for the majority of these children asthma continues into adult life. Therefore, developing good decision-making skills at a young age could optimise long-term health outcomes. There is a paucity of research that examines how a child and their parent may share decisions with respect to asthma management, particularly from the child's perspective.

**Methods**

A qualitative descriptive study that explored who, what, when and why asthma management decisions occur and are shared between children, 7 to 11 years of age, and their parents. Seventeen participants were recruited, 8 children, 8 parents and 1 grandparent. Data was captured undertaking in-depth individual interviews, using an arts based activity at the beginning of the child interviews to build rapport with the child. Framework approach underpinned data analysis.

**Findings**

A dynamic model of the way children and parents transfer, shift and share asthma management decisions was uncovered. A conceptual framework was initially developed from the theoretical perspectives relating to child and parent shared decision-making and subsequently revised to integrate findings from the data analysis of the children's and parent's accounts.

**Conclusion**

The thesis uncovers new knowledge that asthma management decisions between children and parents are non-linear, with responsibility transfers from child to parent under different conditions; whether the child or parent dominates, across contexts and individual child/parent preferences. Understanding the shifting/sharing process of decisions has the potential to assist health care professional practice to support child-parent decision-making in asthma, working with the family and as the child develops.

## Context of child-parent shared decision-making in asthma

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### 1. Introduction

The focus of this PhD thesis is child-parent shared decision-making in the context of the management of childhood asthma within the family. Asthma is a common childhood condition which is largely managed at home, yet there is a paucity of research exploring the management of asthma in the family setting and in particular the way children and parents share decisions related to asthma management. For children and young people with a long-term condition, child-parent shared decision-making has been identified as the optimal approach to managing the child's condition to ensure positive health outcomes (Helgeson *et al.*, 2008). Understanding child-parent shared decision-making could help healthcare professionals assist children to develop effective decision-making skills and support both children and parents to foster autonomy in the young person. This study explored child-parent shared decision-making for asthma management from the perspectives of children aged between seven and eleven years of age and their parents/carers. This thesis is organised into nine chapters:

- Chapter 1 provides an overview of asthma, associated health policies, the context of child-parent shared decision-making within the family and the background and rationale for the study undertaken as part of this thesis;
- Chapter 2 explores the theoretical perspectives that help explain child development and how the child and family respond to living with a child with a long-term condition;
- Chapter 3 critically reviews the current literature pertaining to child-parent shared decision-making in children with long-term conditions, to examine the gaps of what is and what is not known on the topic;
- Chapter 4 describes the methodology of the empirical study including: the aims and objectives of the study; rationale for the study design; development of the interview topic guide; sampling strategies, including the inclusion and exclusion criterion; data

analysis method and processes; and the ethical considerations relating to undertaking research in the family environment;

- Chapter 5 describes 'Who', 'What', 'When' and, 'Why' aspects of the asthma management decisions;
- Chapter 6 explains the independent, shifting and shared decisions and the contextual influences of these decisions;
- Chapter 7 presents the conceptual framework and discussion of findings;
- Chapter 8 presents the study strengths and limitations, issues of rigour and reflective accounts;
- Chapter 9 presents the conclusion, implications for practice and future directions.

### **1.1 Thesis aims and objectives**

This thesis aims to explore child-parent shared decision-making in the context of the management of long-term conditions in children.

The specific objectives are to:

1. Critically analyse the theoretical perspectives relating to how children with a long-term condition begin to learn to manage and take responsibility for their own health;
2. Explore the process of child-parent shared decision-making in relation to the management of a child with a long-term condition;
3. Identify child and parent perceived barriers and facilitators of child-parent shared decision-making in relation to a child with a long-term condition;
4. Add to the theory of child-parent shared decision-making, through the development and extension of a theoretical model to guide practice for health care professionals.

## 1.2 Context

Asthma is the most common long-term illness in children, affecting 1.1 million children living in the UK (National Institute for Clinical Excellence (NICE), 2013), with a child admitted to hospital every 18 minutes for emergency treatment to help them breathe (Asthma UK, 2010a; Asthma UK, 2007). For the majority of these children asthma continues into adult life. Therefore developing good decision-making skills at a young age could optimise long-term health outcomes (Hanna *et al.*, 2012). Although asthma is commonly diagnosed in young children, a definitive diagnosis is uncommon in children less than five years of age (Scottish Collegiate Guidelines Network/British Thoracic Society (SIGN/BTS), 2013). The combined cost of asthma care for both children and adults is estimated to be £2.5 billion annually, approximately £900 million directed towards public health delivery, 50% of this expenditure towards the 20% of individuals with severe asthma (SIGN/BTS, 2013; NICE, 2013; Asthma UK, 2010a; Asthma UK, 2004).

The likelihood of being admitted to hospital because of asthma related symptoms is disproportionate across UK. People living in the North West of England are 65% more likely to be admitted to hospital with asthma related problems, compared to the North East of England (Asthma UK, 2007). A number of factors are associated with the inequalities of health, including socio-economic deprivation. In particular Lancashire, the location for this study, has been identified as an area of deprivation with many children identified as being in poverty and where academic achievement is poor (North West Public Health Observatory, NWPHO, 2009). There is a strong relationship between the Index of Multiple Deprivation and the Children and The Young People's Health Indicators (NWPHO, 2009). Children living in poverty are more likely to have been diagnosed with asthma than children from more affluent areas, 22% and 17% respectively (Joint Health Surveys Unit, 1998). Children from lower socioeconomic backgrounds are more than six times as likely to experience an asthma attack compared to children from more affluent families, possibly due to a higher education level within the more affluent families, facilitating attendance at asthma reviews and increased knowledge of preventive behaviours (Gendo and Lodewick, 2004). Although inequalities in health exist, with appropriate adult support, enabling the child to take an active role in their asthma

management, may lead to improved self-monitoring in settings where an alternative adult is in loco parentis, for example school and sleepovers.

My interest in children with asthma developed when employed as a school nurse which included working with children with long-term conditions, in particular children with asthma. My role included facilitating teaching sessions to staff, children and their families within the school on respiratory disorders. I became concerned that children with asthma did not participate in the full range of school activities as a result of acute asthma exacerbation and days absent from school, despite a range of government policies promoting the health and well-being of children within the school environment including: the importance of the school nursing role in public health within the school community (DH, 2011); the National Healthy School Programme (Department of Health, DH, 2004b); the Children's Plan (Department for Children, School and Families, DCSF, 2007); and Healthy Weight, Healthy Lives (DH, 2008). There appeared to be poor implementation of these policies within practice (Gill and McNeish, 2006). Ensuring young people have the skills to manage their own asthma and share decisions with parents and health care professionals could improve symptom control and enable young people to participate fully in school and everyday life (Sandsund *et al.*, 2011; Tates *et al.*, 2002; Stohlfer *et al.*, 1998).

The Every Child Matters: Change for Children framework (Department for Education and Skills (DfES) /DH, 2005; 2004a) aims to ensure every child's potential is maximised and is based on five outcomes; be healthy, stay safe, enjoy and achieve through learning, make a positive contribution to society; and achieve economic well-being. It is anticipated that findings from the study undertaken as part of this PhD will contribute to these outcomes by assisting children with asthma to be healthy, stay safe and achieve their potential. In relation to long-term conditions health policy in England explicitly advocates actively engaging individuals in the management of their condition and improving services and the overall experience for individuals with a long-term condition (DH, 2007; DH, 2001). Empowering individuals to become managers of their own condition is fundamental to the future of healthcare delivery (WHO, 2002) and is embedded within 'The Expert Patient Programme' within the UK (DH, 2001). When the individual is a child, supporting them to manage and make decisions about their condition involves engaging and

developing effective partnerships with the child, their parents and wider family as appropriate. There is a noticeable absence of specific reference to developing the role of child /parents/ family as experts in managing the child's long-term condition within the expert patient initiative (DH, 2001). This was recognised within the National Service Framework for Children (DfES/DH, 2004b). Consequently self-management programmes for young people who are making the transition to adult services and parents living with children with long-term condition have been developed (DH, 2007). A systematic review provides strong evidence on the effectiveness of self-care support interventions for children with asthma (Kirk *et al.*, 2013).

The Royal College of Paediatrics and Child Health (2003) in England advocate that young people need support to manage their long-term condition with particular emphasis on developing positive health behaviours that continue into adulthood. The report highlighted the importance of child-parent shared responsibility for health decisions as one of the stages of the transition of care responsibility. While parents may need reassurance to let young people take charge of their health needs, offering guidance about sharing decision with their child may foster an easier transition. In the context of asthma, understanding child-parent shared decision-making could assist healthcare professionals support the child and family in managing the child's condition. The child's ability to manage health issues is underpinned by the child-parent relationship and to conduct child health research requires an understanding of this relationship (Lutz *et al.*, 2009). The seminal work of Blake (1954) has continued to gain support from developmental and social science research in the understanding of child-parent relationships (Lutz *et al.*, 2009).

Understanding child-parent decision-making in the context of children with long-term conditions is important because of the potential to facilitate the transition to greater decision-making independence (Miller, 2009). Parent's attitude is more influential on the child's level of participation in decision-making than the child's actual competence (Martenson and Fagerskiold, 2007). Decision-making may improve the child's knowledge and understanding of the condition; enable more accurate risk perceptions, resulting in greater participation in the management of their condition. Shared decision-making has

the potential to improve treatment adherence and equip the child with the skills that will improve their confidence and coping strategies (O'Connor *et al.*, 2009; Murray *et al.*, 2005).

Effective management of asthma requires taking prescribed treatment, recognising acute illness symptoms and responding to specific triggers. For the child to be active in the management of their asthma requires a range of cognitive and behavioural skills.

Cognitive development has been identified as a salient factor in the development of autonomous decision-making (Hanna, 2012). If the child has the knowledge and experience to recognise the early signs of an acute asthma episode, responding appropriately and seeking health care advice is more likely.

### **1.3 Overview of asthma**

Management of asthma has evolved from symptomatic relief to include the prevention of acute exacerbations. Appreciating how a child and/or their parents manage asthma requires an understanding of the asthma aetiology, the severity classification of childhood asthma and treatment options.

#### **1.3.1 Aetiology**

Asthma is a disorder of chronic airway inflammation, characterised by wheeze, cough, difficulty breathing and chest tightness (SIGN/BTS, 2013, 2011). Symptoms present with visual cues including breathing difficulties and/or coughing, which are visible to the parent, carer or teacher (Welch, 2000). Other symptoms such as chest pain, anxiousness or restlessness can only be experienced by the child, highlighting the importance of a child being actively involved in decisions about their asthma management (Beers, 2003). In acute exacerbations the child may also appear cyanosed, confused and feel lethargic (Beers, 2003).

Although the cause of asthma is unknown, genetic and environmental factors are identified as contributing factors (Bierbaum and Heinzmann, 2007). Common allergens that can potentially trigger an asthma attack include: dust; dampness in the house; cigarette smoke; animal dander; perfumes and certain food types. The most common



non-allergenic triggers include: changes in weather conditions; exercise; associated with other conditions such as common cold; and extreme emotions (Walters *et al.*, 2005; Pradel *et al.*, 2001; Welch, 2000). Allergies affect up to 80% of children with asthma, requiring the child and family to understand acute allergic reactions to enable them to manage the child's long-term condition and ensure optimum health (Welch, 2000). Research findings suggest an association between air pollution and exacerbations of asthma (BTS/SIGN, 2011). However, further research is needed to ascertain the impact of indoor pollutants on asthma symptoms, for example the effectiveness of strategies to reduce the number of house mites and the relationship with the severity of asthma symptoms. In addition, the impact of restricting pets (particularly cats), on reducing the asthma symptoms is inconclusive. Current guidelines recommend adults should not smoke within the house because of the impact on the child which is associated with an increased use of bronchodilator medication and long-term use of inhaled steroids (BTS/SIGN, 2013).

### **1.3.2 Classification of asthma severity**

The Scottish Intercollegiate Guidance Network in conjunction with the British Thoracic Society (SIGN/ BTS, 2013) classified asthma in relation to the frequency and impact of symptoms:

- **Mild asthma:** daytime symptoms more than once a week, night-time symptoms more than twice a month, may affect activity and sleep;
- **Moderate asthma:** daily daytime symptoms between exacerbations, exacerbation at least twice per week, restricted activity and sleep disturbance;
- **Severe asthma:** continual daytime symptoms between exacerbation, frequent night-time symptoms between exacerbations, exacerbations occur frequently and affect activity and caused sleep disturbance.

The classification system aims to ensure the child receives the appropriate level of care (SIGN/ BTS, 2013). Children with mild asthma are monitored by the asthma nurse within their general practitioner's surgery. Children with moderate to severe asthma are monitored by health care professionals within the asthma clinic of a designated hospital outpatient department. The classification of asthma determines the treatment

implemented and once a provisional diagnosis of asthma is made, a child will commence treatment.

### **1.3.3 Treatment**

The management of asthma primarily involves the child being prescribed inhaled medication; prophylactic (preventer) inhalers taken daily to reduce chronic symptoms and prevent acute exacerbations and inhaled bronchodilator (relieving) agents to treat acute breathing difficulties. The appropriate use of preventative treatment is pivotal to the management of asthma (Newbould *et al.*, 2008). It is important for the child and parent to understand the importance of making good decisions about asthma management because an acute asthma attack is often a result of poor management and if not recognised and treated promptly may be fatal (BTS/SIGN, 2009). In addition, poor managements can result in repeated hospital attendance; of the children requiring emergency treatment for asthma related symptoms, over 15% will re-present within two weeks (Emerman *et al.*, 1999).

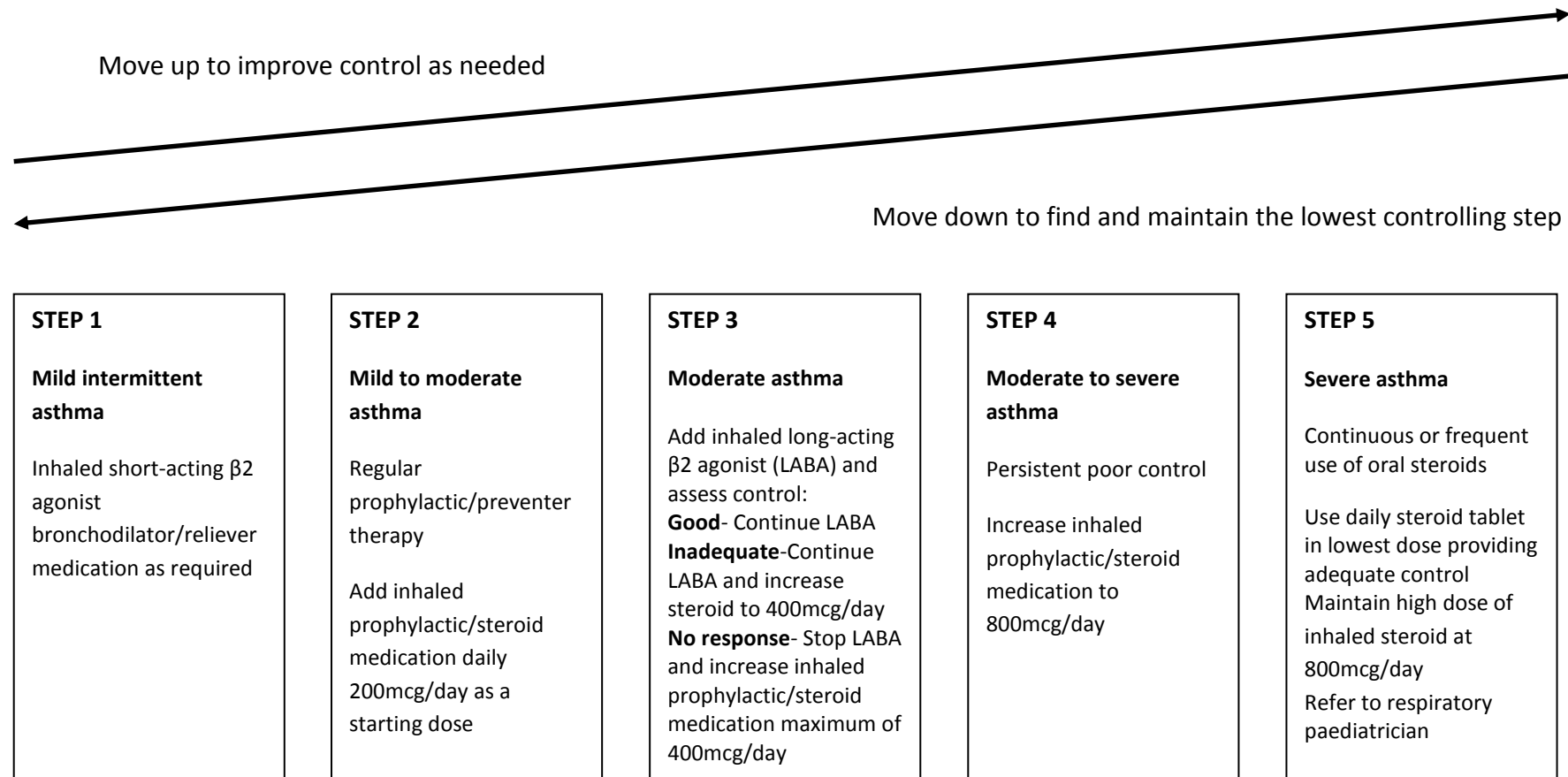
The 'stepwise' treatment protocol, presented in Figure 1, provides health care professionals with pharmacological guidance about managing a child with asthma. Health care professionals have responsibility for assessing the child in order to ensure treatment commences at the step most appropriate to the severity of illness symptoms. Before a change in treatment the health care professional must confirm the degree of illness severity, ascertain concordance with medication, check the inhaler technique and identify any trigger factors. If the child's asthma is not well controlled, treatment is reviewed every three months ensuring the stepping up or down of treatment is undertaken in a timely manner, optimising the child's health (SIGN/BTS, 2013).

Improved self-management may prevent hospital admissions, in 80% of the cases asthma symptoms developed over 48 hours, during which time appropriate interventions could have been implemented (SIGN/BTS, 2013; Kolbe *et al.*, 1998). Research suggests children and parents underestimate the severity of their asthma with an over-reliance on bronchodilator medication rather than effective preventative strategies (Gustafsson *et al.*, 2006; Couriel *et al.*, 1986).

#### **1.3.4 Concordance with treatment**

Adherence to treatment regime and being proactive in responding to acute symptoms may improve lung function, lower use of emergency services, increase self-efficacy and reduce school absenteeism (Guevara *et al.*, 2003). Successful management strategies implemented by the child and parent can potentially minimise the disruption of asthma on their everyday lives (Peterson-Sweeney, 2008). The management of asthma in children is a shared responsibility between children, parent(s), close family members and healthcare professionals.

**Figure 1: Summary of 'stepwise' management in children 5-12 years of age (BTS/SIGN, 2013)**



Children and their parents are responsible for the day-to-day management of their child's asthma which includes monitoring symptoms, managing medications, seeking medical assistance and interacting with health care workers (Buford, 2004). Health care professionals' priorities relate to the effective management of asthma and include concordance with the medical regime, educating the family and the avoidance of trigger factors (Welch, 2000).

Evidence suggests that concordance with medical care and treatment is better in children younger than twelve years of age compared to older children (Zindani *et al.*, 2006; Jonasson *et al.*, 1999). A possible explanation is younger children have greater reliance on their parents in relation to decisions about the management of their condition, therefore are likely to be more compliant with treatments.

The term 'concordance' refers to a process of shared goal setting, typically between patients and health professions (Royal Pharmaceutical Society of Great Britain, 1997). Compliance with treatments dominates the health literature which refers to the patient adhering to treatments or medication as prescribed by the health care professional rather than a collaborative process (Dinwiddie and Müller, 2002). The dominance of compliance within the literature relating to asthma management does not reflect a patient centred approach to care where decision-making is central. Deliberate non-compliance occurs when there is refusal to take the medication which may be because of a fear of the side effects or rejecting the advice provided by the health care professional (Dinwiddie and Müller, 2002).

Participating in decision-making may reduce risk taking behaviours such as non-concordance with medication, non-avoidance of triggers and being alert to and acting on early warning signs of asthma symptoms. Children are able to share in the decision-making of the use of their inhaler for the treatment of asthma more readily than parents envisage (Robinson and Delahooke, 2001). However, the child's decision to take preventive asthma medication is often not maintained as prescribed which may be a consequence that a lack of symptoms suggests that the medication is not essential (Buford, 2004).

In relation to child health setting there are two issues: first, there appears to be a paucity of evidence relating to concordance in asthma management in young children. Second, the

child-parent dyad and association with treatment decision-making is an under researched area (Hanna *et al.*, 2012). In addition, it has been suggested that unintentional non-compliance may be a result of family disorganisation and poor family function or a lack of understanding how to administer medication (Dinwiddie and Müller, 2002). A range of factors have been identified as influencing compliance with treatments, including: the child's personality and motivation; the effectiveness of information sharing, education and support from health care professionals; severity of asthma symptoms; lifestyle; and peer pressure (Couriel, 2003). Consistent family routines have been identified as factors that can improve compliance with the medical treatments and consequently reduce asthma morbidity (Peterson-Sweeney, 2008).

#### **1.4 Impact of asthma on the child**

Asthma can affect the physical, emotional and social aspects of a child's life. Admissions to hospital due to asthma symptoms impacts on the child's attendance at school and educational achievements; participation in leisure activities; developing friendship which may impact negatively on their self-esteem and behaviour (Cashin *et al.*, 2008; Joseph *et al.*, 2005; Wade *et al.*, 1997). The presence of asthma symptoms can have a significant impact on a child's daily activities because of sleep deprivation due to night time coughing and wheezing. Seventy six per cent of children report disruption to their daily life (Kaur *et al.*, 1998) and seventy four per cent of children describe an asthma attack when recollecting an incident when they felt ill (Pradel *et al.*, 2001), highlighting the disruption of asthma on their lives. Once diagnosed with asthma the child has to begin a psychological adjustment to living with a long-term condition. This section will outline the impact of asthma in relation to school attendance, developing friendships and peer acceptance, leisure and psychological adjustment to a long-term condition.

##### **1.4.1 School attendance and performance**

Approximately a third of children report their asthma symptoms were severe enough to prevent them from attending school for approximately ten days per month (Dean *et al.*, 2010; Eggleston *et al.*, 1997). Over 12.8 million school absences each year are as a direct

consequence of asthma symptoms (Centres for Disease Control and Prevention, 2002). However, research has identified that effective support from school health services can result in a similar level of academic achievement similar to a child without asthma (Millard *et al.*, 2009; Milton *et al.*, 2004). However, coughing has been identified as a salient symptom affecting the child's concentration in school and impacting on their educational achievements (Basch, 2011; van den Bernt *et al.*, 2010; Moonie *et al.*, 2008; Celano and Geller, 1993).

#### **1.4.2 *Developing friendships and peer acceptance***

Children aged between six and twelve years report being bullied, which they attribute to symptoms such as dyspnoea, wheezing and coughing, which they perceive annoy their peers (van den Bernt *et al.*, 2010). Children living with asthma describe frustrations in relation to convincing their peers that the absence from school was genuine (Yawn, 2003). Yet, evidence suggests children are supported by their peers and often develop strong bonds with a special friend, who may also accompany them to visit the school nurse if they require treatment (Fereday *et al.*, 2009). Supporting children to communicate effectively about their asthma with their peers has been highlighted as one way that children can develop peer relationships (van den Bernt *et al.*, 2010; Kurnat and Moore, 1999). Children are eager to be accepted by their peers and do not want to appear different to other children not experiencing a long-term condition (Fereday *et al.*, 2009). Lack of privacy in school is a major concern to children when they take their medication, which may lead to non-adherence of the medication (Smith *et al.*, 2008). Research has highlighted that effective management strategies such as the administration of prophylactic medication to ensure the child's asthma is well controlled can increase the child's acceptance with their peers (Prout *et al.*, 1999). However, parents perceive that administering the child's inhaled bronchodilator in public is often met with friction from their child because this draws attention to their asthma and makes them different from their peers (Yawn, 2003).

#### **1.4.3 *Impact of asthma on leisure activities***

An acute exacerbation of asthma may impact on a child's participation in leisure activities, which can have social implications due to self-imposed restrictions of physical activity

(Williams *et al.*, 2010). Children express feelings of anger and frustration living with asthma restricting their participation in leisure activities (Gabe *et al.*, 2002). To minimise the limitations and disruption asthma can impose on a child's life, they may expose themselves to known triggers such as close proximity with animals, playing out and participating in leisure activities for example sport, as they want to be seen as 'normal' (Fereday *et al.*, 2009; Kratz *et al.*, 2009; Meng and McConnell, 2002; Pradel *et al.*, 2001; Prout *et al.*, 1999). The level of participation within physical activity is often dependent on parental support and negotiation with health care professionals. Girls are more likely to adapt to a long-term illness rather than just learning to live with it and are more likely to discuss their illness with peers, family and friends (Charmaz, 1995). Girls think it is necessary that their friends are aware of their illness in the event of an emergency (Williams, 1999). In contrast boys are more likely to be covert in an attempt to minimise the impact of asthma on their life (Williams, 1999). Boys perceive that disclosing they have a long-term illness to friends will reduce their masculinity and peers will view them differently (Iley, 2014; Williams, 1999). Higher expectations are placed on girls to self-manage their long-term condition (Iley, 2014; Williams, 1999), as they are considered to be more responsible than males (Iley, 2014; Graham, 1984). If girls are unable effectively to manage their asthma, this may result in poor control of the illness due to the higher expectations which may impact on approaching parents for assistance.

#### **1.4.4 Psychological adjustment**

Many children describe feelings of fear, panic and have expressed an awareness that they could die during an exacerbation of asthma (Gabe *et al.*, 2002). However, although these feelings often decrease as the child learns to manage their asthma more effectively, some young people describe that the feelings of fear and panic never diminish (Gabe *et al.*, 2002). Children who have difficulties contributing to the management of their long-term condition are more likely to experience anxiety related disorders compared to children not living with a long-term condition (Lavigne and Faier-Routman, 1992). Evidence suggests children who experience high levels of anxiety are more likely to live in families where parents have difficulty adapting to living with a child with a long-term condition (Drotar, 1996). Parents who are anxious about their child's condition are more likely to retain responsibility for the



management of the child's condition and subsequently prevent the child becoming actively involved in care decisions (Baron, Veilleuz and LaMarre, 1992). Parenting styles (Maccoby and Martin, 1983, Baumrind, 1967) may also affect the level of child participation within the asthma management decision-making and are discussed in Chapter 2, Section 2.3.3.

### **1.5 Impact of asthma on the family**

Living with a child with a long-term condition requires parents to assume the role of care coordinator and medical expert, in addition to parenting roles (Hafetz and Miller, 2010; Fereday *et al.*, 2009; Ray, 2002, Williams *et al.*, 2007). Evidence suggests both good and poor adjustment within families living with a child with a long-term condition (Yawn, 2003; Jerret and Costello, 1996). For children with asthma, everyday management occurs at home, which can result in anxiety and emotional exhaustion for parents because of being 'hyper-vigilant' in being alert to acute illness symptoms (Zebrack *et al.*, 2002). Despite having additional needs, children and their parents endeavour to instil a sense of normality within their family routine. Living with a long-term condition does not necessarily place the child at risk to poor health outcome but when associated with a lack of family routine can impact on the child's quality of life and increased morbidity (Fereday *et al.*, 2009; Peterson- Sweeney, 2008; Markson and Fiese, 2000).

Living with a child with a long-term condition presents challenges and demands on the whole family and can impact on family functioning (Fereday *et al.*, 2009). Evidence suggests children with asthma and their families have concerns about: the impact on the child's learning because of frequent absenteeism from school; unpredictable absence from work causing parental anxiety; restrictions to social and leisure activities; uncertainty of the nature of acute exacerbations of the asthma; and managing the child's asthma effectively (Fereday *et al.*, 2009; Kurnat and Moore, 1999). Parents describe difficulties in juggling family commitments, financial constraints and maintaining family relationships (Yawn, 2003). Parents of a child with asthma report that family dynamics changed following their child's diagnosis and describe feelings of guilt that their child with asthma consumes their time, often at the expense of their siblings (Yawn, 2003). However, children are positive

about their relationship with their parents and perceive they are treated similar to their siblings (van den Bernt *et al.*, 2010). Managing a child's asthma demands energy, time, financial resources, can cause a strain on family relationships; can impact on family privacy; may impact negatively on the family's wellbeing; and can contribute to social isolation (Kratz *et al.*, 2009; Kurnat and Moore, 1999). Family routines are often centred on the child with asthma and during an acute exacerbation of symptoms planned social activities are likely to be cancelled (Yawn, 2003). Asthma impacts on the family because the daily management such as adherence to medication, acknowledging early warning signs of asthma symptoms, meticulous household cleaning, responding to acute symptoms and attending health care appointments have to be incorporated within daily family life (Miller, 2009; Peterson-Sweeney, 2008; Fiese *et al.*, 2008; Brown *et al.*, 1996; Lenney *et al.*, 1994).

Evidence suggests that mothers perceive they have overall responsibility for managing their child's asthma on a daily basis and responding to acute asthma symptoms in emergency situations (Dickinson and Dignam, 2002; Pradel *et al.*, 2001; Markson and Fiese, 2000; Williams, 1999). Children view their mother as their primary carer (Mayall, 2002). However, mothers can be overprotective and restrict the child's contribution in the decision-making especially with boys (Williams, 1999; Smith, 1998). Children and families report a desire to be in control of their lives which can be achieved if families, health care professionals, school staff and the communities work collaboratively, facilitating the child and family's ability to live well with asthma (Yawn, 2003).

## **1.6 Decision-making in the child health setting**

Decision-making in health care typically relates to the partnership between the health care professional and the patient when choosing between treatment options (Charles *et al.*, 1997). Decision-making challenges the paternalistic model of healthcare which reflected a one way information exchange from the health care professional to the patient (Parsons, 1951). Research about decision-making has focussed primarily on treatment decisions because deciding between treatments has traditionally been a shared activity (Charles *et al.*, 1999). Literature relating to patient-doctor collaboration has primarily focussed on the adult

patient and there is a paucity of research on shared decision-making in the child health setting. Parents of children with a long-term condition develop expertise in their child's condition and often assume the role as the manager (Ray, 2002). Consequently when the patient is a child, the parent often assumes the role of decision-maker. However a tripartite relationship exists involving the child, parent and health care professional. In the home environment the 'paternalistic medical model' is potentially mirrored in the child-parent dyad, where the parent assumes the role of the professional taking responsibility for and deciding treatments with or without negotiation from the child. Child-parent shared decision-making offers an opportunity for the child to participate within the decision-making process (MacKean *et al.*, 2005). The SIGN/BTS guidelines (2013, 2011) outline strategies to involve the family within the child's asthma management at home and in partnership with health care professionals to include: non-pharmacological management of primary prevention (parents advised against smoking around their children); secondary prevention (reduce exposure to housemites); complementary therapy (family therapy); pharmacological management using the 'step-wise' approach; stepping down; and exercise-induced asthma.

Factors essential for effective collaboration between child, family and health care professionals include mutual trust and respect and health care professionals facilitating both the child and family to participate within the care decisions (Blue-Banning *et al.*, 2004). Policy guidance has emphasised children should be acknowledged as competent in participating in health decisions (DH, 2002) and have a right for their voice to be heard about decisions that affect their life (United Nations, 1989). Children have traditionally had little involvement in health consultations or the shared-decision-making model of healthcare (Butz *et al.*, 2007). Yet research has found that children as young as two years of age are able to discuss their health and treatment needs (Borzekowski, 2009; Nova *et al.*, 2005) and from eight years of age children can contribute to the management of their asthma and initiate appropriate medication (Winklestein *et al.*, 2000). Effective communication between health care professionals and children during consultations has the potential to increase symptom control and concordance with the medication (Couriel, 2003). Within the British Asthma Management Guidelines there is minimal reference to effective ways of engaging with children about their asthma, compared to an abundance of information on pre-school

children presenting with a wheeze (SIGN/BTS, 2013). Dependent on their experience and maturity children are able to participate within decision-making at four levels: being informed; expressing a view; influencing the decision-making; being the main decider (Alderson and Montgomery, 1996). The first three levels demonstrate the child's varying levels of decision-making with an adult, for example sharing the decision with their parent. The fourth level suggests the child is able to make an informed decision independently (Alderson, 2008; Alderson and Montgomery, 1996).

### **1.7 Children's involvement in their health care**

Children with asthma perceive the doctor's role as performing a physical examination and providing advice regarding the condition or treatments (Newbould *et al.*, 2008). Many children perceive that health care professionals communicate with them inappropriately, using language more suitable to young children (Couriel, 2003). However it has been suggested children want to take a more active role within the consultations, which requires health care professionals to value the child's contribution to consultations and facilitating the child's participation using age appropriate communication strategies (Iley, 2014 and Couriel, 2003). A more patient-centred approach within the consultations is required to reduce the barriers experienced by young people (Triggle, 2013; Couriel, 2003). Strategies for child inclusivity within the consultations include using visual aids to communicate, encourage turn taking with the doctor and asking the child to clarify the salient points of the consultation (Butz *et al.*, 2007). However, children generally prefer parents to act as an intermediary when making essential or important care decisions, suggesting a child-parent shared decision-making model may already operate (Miller, 2009).

Depending on their age and stage of development and cognitive and behavioural skills, a child has the potential to contribute to the management of their long-term condition. Children aged seven to eleven years of age spend greater amounts of time away from the family home for example at school and engaging in leisure activities with friends. Away from the home environment, the teacher is the adult a child spends the most time with (Iley, 2014). At this age children are developing greater autonomy with more logical reasoning

processes (Pradel *et al.*, 2001; Wadsworth, 1989). If the child is better informed about their asthma and actively involved in the management of their condition, in parental absence they are empowered to make informed decisions about their asthma optimising their health and well-being (Meng and McConnell, 2002).

Some children aged five to eleven years of age have the cognitive ability to understand and implement health preventive actions (Watts, 2008). Evidence suggests that a child as young as three years of age is able to engage with health related activities (Borzekowski, 2009). However, young children are unlikely to understand the physiological processes of asthma as well as an older child and tend not to recognise the early warning signs of an exacerbation (Meng and McConnell, 2002; Pradel *et al.*, 2001). This may be due to early warning symptoms not immediately impacting on their physical functioning. Young children are able to recognise acute symptoms and respond appropriately using inhaled medication during an acute asthma exacerbation (Buford, 2004).

Younger children are unable to distinguish between the prophylactic (preventer) inhaler and inhaled bronchodilators (reliever) medication and often identify the inhaler by colour (Pradel *et al.*, 2001). Children less than seven years of age are unable to detect early signs of deterioration in their asthma (Buford, 2004; Pradel *et al.*, 2001). Children twelve years of age and to some extent children seven to twelve years of age are aware of the triggers of their asthma but do not demonstrate avoiding these allergens. This may be due to their strong sense of external locus of control acting as a barrier to their perceived control of the asthma (O'Brien *et al.*, 1989).

Adherence to prescribed medication for asthma is poor in adolescence (Williams *et al.*, 2007; Wales, 2007; McQuaid *et al.*, 2003; Es *et al.*, 2002; Lillymen and Lennard, 1996) and is the transitional period where children undergo rapid development and assume greater self-management responsibilities for their health. Adolescence is also a period of risk taking behaviours and young people require guidance about employing rational decisions (Beck, 1999; Giddens, 1999). If decision-making skills can be fostered prior to adolescence, the young person may be better able to make health care choices and more able to self-manage their asthma. It is likely that if children participate within the decision-making at a younger

age they will find the transition to self-management more efficacious (Naimi and Apter, 2010; Miller, 2009).

Child-parent decision-making involves children and parents negotiating, compromising and brainstorming ways effectively to manage their asthma (Aynsley-Green, 2000). Collaborative working enables the child to participate within the decision-making process without taking on full responsibility for autonomous decisions (Miller, 2009). Children know their bodies well, enabling them to participate within the decision-making process (Meah *et al.*, 2009). Factors facilitating the decision-making from parent to child control are: parents' perceptions of the benefits of transferring responsibility; children's perceptions of the benefits; and the available physical, social and psychological resources to support such a transfer (Williams *et al.*, 2007). If the child becomes autonomous within the management of their asthma at an earlier age, the consequence of increasing adherence to treatment during the adolescent years is likely to be increased (Borzekowski, 2009; Wales, 2007), as the health behaviours adopted throughout childhood extend into adolescence and adulthood (Hancox *et al.*, 2004).

Evidence suggests children demonstrated a positive significant relationship between self-management of asthma and their self-efficacy belief towards asthma (Kaul, 2011). Although some children worry about their asthma symptoms, they often choose to ignore the early warning signs as they wish to appear normal to their peers and only acknowledge the symptoms when they progress to a late stage. The presence of asthma symptoms is often the reason for seeking parental assistance (Meng and McConnell, 2002). However, the child's disclosure of the symptoms is selective in terms of what information they disclose because they want to: avoid treatment or activity restrictions; to prevent their parents from worrying; and wanting to appear strong (Hafetz and Miller, 2010; Miller, 2009). The child's lack of disclosure of illness symptoms may have a detrimental effect on their long-term illness, with some children only reporting their worsening symptoms when they felt unable to manage and consequently delaying the treatment required for symptom relief (Hafetz and Miller, 2010; Miller, 2009). Where this occurs, the parents may be less likely to include the child in future decisions regarding asthma management.

## **1.8 Summary**

This chapter has outlined the impact of living with a child with asthma. Child-parent shared decisions about the management of the child's asthma with support and guidance from health care professionals has the potential to optimise the control of asthma symptoms reducing emergency admissions. Benefits of the child being actively involved in the management of their long-term condition include less disruption to the family, improved school attendance which could potentially improve the child's academic performance, facilitate friendship groups and increased psychological adjustment of a long-term condition. Improving the management of long-term conditions in children is central to current policy directives, particularly collaborative health care practices. Promoting optimal child-parent shared decision-making when the child is young and facilitating the transition to greater decision-making independence could provide the foundation for effective asthma management for adolescence and adulthood. Despite this, the concept of child-parent decision-making has not been extensively researched but if understood and fostered within health care practice, it may improve asthma management from an economic, social and health perspective. The following chapter will explore the theoretical perspective relating to childhood long-term conditions particularly focusing on: understand why children and their parents make health choices; children's cognitive development and ability to learn; and how families respond when a child has a long-term illness.

**2. Introduction**

This chapter critically evaluates the theoretical perspectives on child development and the family's response to living with a child with a long-term condition, to understand how decisions are made about the child's condition. Theoretical models have been widely used to explain factors that influence participation in health related activities. The models presented, because of their relevance to the context of child-parent shared decision-making include: the Health belief model (Becker, 1974), Parent-child transfer of asthma responsibility (Buford, 2004) and Family systems theory (Bronfenbrenner, 1979). A detailed critique of Buford's (2004) theoretical model for child-parent transfer of asthma responsibility is offered as it has specific relevance for the focus of this thesis.

Evidence suggests that children and young people actively contribute to the management of their long-term condition (DH/DfES, 2004b) and understand the impact of illness symptoms (Meah *et al.*, 2009) which ideally positions them to participate in health decisions. However, the child's developing cognition and reasoning skills will influence how they perceive and organise their world (Corsaro, 2005). Therefore an analysis of child development, cognitive (Donaldson, 1978; Vygotsky, 1978, Piaget; 1969) and learning theories (Bandura, 1997, 1989; Rotter, 1966, 1954), is central to understanding child-parent shared decision-making in the context of asthma management. The rationale for exploring theories is to:

- Understand why children and their parents make health choices;
- Explore and explain children's cognitive development and ability to learn;
- Examine how families respond when a child has a long-term illness;
- Inform the research design and methods for the empirical study;
- Develop an understanding of undertaking research sensitively with children.



The critical analysis of the models and theoretical perspectives have been synthesised to develop a conceptual framework of the factors influencing child-parent shared decision-making when managing a long-term condition (page 40), which informed the literature review (Chapter 3), study design (Chapter 4) and contributed to the explanation and interpretation of the study findings (Chapters 5 and 6) and discussion (Chapter 7).

## **2.1 Health Belief Model**

The biomedical model of health was a dominant model within healthcare in the mid-nineteenth century and was based on a reductionist philosophy, assuming that an individual had no control over their illness (Janz and Becker, 1984). The focus of healthcare delivery centred on diagnosis and treatment with health care professionals operating in a paternalistic paradigm. Whereas, the biopsychosocial model shifted from the linear biomedical model of health to a model which integrated psychological, environmental and sociological factors impact on both health and illness (Engel, 1980; 1977). Determinants of health behaviours include; modelling and social norms; genetics; emotional factors, such as fear, anxiety and stress; perceived symptoms such as breathlessness; and individual health beliefs (Leventhal *et al.*, 1985). However, health beliefs have been identified as central determinants to predicting an individual's health choices (Janz and Becker, 1984).

The Health belief model draws on individual psychological and behavioural factors to explain how beliefs influence health choices (Janz and Becker, 1984). Originally the model was developed by Rosenstock (1966) then modified by Becker (1974) in response to research that found health behavioural intentions could be predicted by the perceived susceptibility and barriers to health action behaviours. The model has been extensively applied to predict health related behaviours such as screening behaviours for cervical smears or self-breast examination (Guvenc *et al.*, 2011), condom use to prevent sexually transmitted infections and unwanted pregnancies (Hall, 2011), vaccination uptake (Brewer *et al.*, 2007) and dietary compliance (Connor and Norman, 1996). Becker and colleagues have frequently updated the model, to incorporate new research and reflect contemporary society further to explain an individual's actions across a range of health related issues (Williams *et al.*, 2007; Pradel *et*

*al.*, 2001; Seydel *et al.*, 1990; Hill *et al.*, 1985; Janz and Becker, 1984; Becker and Rosenstock, 1984).

The four dimensions of the Health belief model (Becker, 1974) are: perceived susceptibility of the illness; perceived severity of the condition and consequences; perceived benefits of the behaviour reducing the impact of the illness; and perceived barriers of executing the health behaviour. A critical review of 29 health belief model-related studies (Janz and Becker, 1984) identified that the strongest predictors of the health related behaviour were: perceived barriers, perceived benefits, perceived susceptibility and perceived severity. Perceived susceptibility of illness correlated to an individual's willingness to undertake the preventative behaviour especially if the perceived benefits outweighed the perceived barriers (Rosenstock, 1974). The model is useful in identifying predictors of health related behaviour for an individual but fails to consider the influence of other people. For example, within this study the relationship between children and their parents, and teachers within the school setting.

A literature review identified many children require prompts for example, parents reminding the child to take preventative inhaler. Few studies identified in the review provided clarity regarding the contribution of 'cues to action' in predicting health actions (Janz and Becker, 1984). This concept has relevance for the focus of this thesis in that it is likely that parents facilitate the child's developing self-management behaviour. Whether health behaviours are adopted is dependent on a child's confidence, their self-efficacy beliefs that they can undertake the health behaviour (Rosenstock *et al.*, 1988) and are related to Bandura's learning theory (1989) discussed in further detail in section 2.2.3.

Long-term conditions are primarily managed at home (von Korff *et al.*, 1997). As outlined in Chapter 1, Section 1.3.4 concordance with management regimes is often poor (Coutts *et al.*, 1992). The Health belief model has often been used to explain the decision-making process influencing health behaviours and poor treatment concordance in children (Williams *et al.*, 2007; Pradel *et al.*, 2001; Janz and Becker, 1984). Three salient areas of health behaviours have been identified, preventive health behaviours, sick role behaviours and seeking health advice (Janz and Becker, 1984) which may explain health behaviour during decision-making

in asthma management across different contexts/situations (Connor and Norman, 1996). For example the person making the decision when the child is symptom free may differ when asthma symptoms are present or more severe.

In the context of children and asthma the health belief model has been developed to explain treatment compliance (Becker *et al.*, 1978; p269) including:

- General health motivations based on general concern about the child's health;
- Perceived illness threat and susceptibility to subsequent asthma attacks;
- Perceived benefits and barriers to compliant behaviour, including confidence in the health care professional;
- Efficacy of the treatment regime in reducing subsequent asthma attacks;
- Disruption to daily activities of the administration of the treatment on the individual;
- Palatability of medications.

However, the influence of the child-parent dyad relationship or the child's perspective on the decision-making process of the management of the long-term condition has been overlooked. As a result, the usefulness of this model when exploring the child-parent decision-making process in the context of the asthma management is limited (Meng and McConnell, 2002). Despite this limitation, the model assists in explaining why children and parents make health choices regarding the child's asthma management and offer explanations to the decision-making processes.

## **2.2 Children's cognitive development and ability to learn**

Cognitive and learning theorists offer differing perspectives on a child's development and provide explanations for the similarities and differences between children at certain milestones and in certain situations. Cognitive theorists explain how the child's actions and behaviours are influenced by the environment and their stage of cognitive development

(Greig and Taylor, 2005; Corsaro, 2005). Learning theorists explain development in terms of an individual's learned behaviour through observing, modelling and experiences (Greig and Taylor, 2005). For a child with a long-term condition understanding the cognitive development and learning theories can guide practitioners when supporting the child and family to share and move towards the child autonomously managing their own long-term condition.

### **2.2.1 Cognitive theories**

Piaget and Vygotsky are the most influential psychologists of cognitive development in children within the last century (Lourenco, 2012; Vygotsky, 1978). Both psychologists perceived the child as an active participant in constructing knowledge and considered biology and the environment important factors in knowledge development. However, Piaget and Vygotsky had different theoretical positions in relation to the way knowledge was constructed (Lourenco 2012; Greig and Taylor, 2005). Piaget (1969) argued that learning comes from inside (autonomy) and language emerges through assimilation and accommodation; whilst Vygotsky (1978) posits higher forms of cognition derive from outside (heteronomy) and through social interactions with adults (Tisdall and Punch, 2012; Lourenco, 2012; Piaget, 1969; Vygotsky, 1978).

A child's learning is supported through the use of language by adults, to gain skills, knowledge, understanding and confidence (Vygotsky, 1978). Vygotsky's perspective may explain the influence parents can have on a child's ability to engage in decision-making. Communication between children and their parents can facilitate the child's learning to increase their zone of proximal development and achieve more complex asthma management tasks (Greig and Taylor, 2005). The theorists agree that adults provide stimulus and environments for children to learn but where Vygotsky suggests that social interaction with an adult is crucial in developing a child's learning, Piaget believes social interaction can have a negative impact on the child's learning (Lourenco, 2012; Piaget, 1969; Vygotsky, 1978). Piaget was a constructivist and believed that children construct their own knowledge (Fraser *et al.*, 2004).

Piaget's work on children's cognitive development has been revised and challenged, but is still widely influential on the way the day-to-day lives of children are structured. For example within education providing a framework to assist teachers' understanding of a child's reasoning and problem solving abilities at different ages, particularly in mathematics and science (Greig and Taylor, 2005; Wadsworth, 1989). According to Piaget's theory (1969), a child aged seven to eleven years is within the concrete operational stage of cognitive development and major changes occur within the thinking of a seven year old (Fraser *et al.*, 2004). A seven year old child is able to apply logical thought processes to existing concrete problems (Piaget, 1969). Hence a child is able to contribute towards some aspects of the decision-making process for the management of their asthma. Piaget argues the child follows each stage in a linear order and has to be a certain age before progression to the next development stage (Piaget, 1969). For this study this means there will be a lower level of participation within the decision-making process from the lower age range children.

Whilst Piaget's theory offers an understanding of children's cognitive ability in relation to their age, it does not capture what children are capable of or allow for the diversity of children's experiences of long-term health conditions such as asthma. In the context of long-term conditions, the child may have greater capacity to become more autonomous because their experiences have increased decision-making and reasoning skills resulting in an ability to rationalise their behaviour and actions (Wadsworth, 1989). In addition, the child may be able to recall prior experiences and apply these experiences to new situations. With respect to asthma management this may involve learned consequences of not using their inhaler when acute asthma symptoms are experienced which influence the use of their inhaler in similar future situations. Piaget (1969) suggests that children between the ages of seven and eleven years can only solve problems that are concrete; in other words they are unable to solve problems that are hypothetical, abstract or involve many variables. Consequently, the child may only be able to apply logical reasoning to symptoms of asthma when they exist. Piaget's theory does not explain how children of the same age may vary in their decision-making ability for asthma management. In a critique of the tasks Piaget used to test a child's cognitive development, Donaldson (1978) argued the tasks were neither natural nor child friendly and underestimated a child's ability to think and reason. Indeed, research found that

children as young as three were able to think logically (much earlier than Piaget claimed) when using appropriate language in a meaningful context with tasks redesigned using a familiar adult, environment and language (Donaldson, 1978).

Although younger children appear to have the ability to think logically, theorists suggest a child between seven and eleven years of age thinks less ego-centrally and can respect and accommodate another person's point of view (Wadsworth, 1989; Piaget 1969). The child is developing the capacity to listen to their parent's perspective and participate in decisions about their care. However, to enable a child to appreciate another person's point of view requires presenting information in a way the child understands (Donaldson, 1978).

Donaldson (1978) focuses on the concept of children constructing knowledge for themselves by actively making sense of their environment, known as embedded and disembedded thinking (Donaldson, 1978). In contrast Piaget (1985) postulated children can only learn when they are ready, which suggests the children seven to eleven years age are unable to generalise information to other situations. For example, the child may not predict asthma symptoms and therefore initiate management tasks such as avoidance of specific triggers.

Tension within the child-parent shared decision-making paradigm may occur as a child's ability to understand and rationalise problems increases and the child begins to challenge the decisions made by others (Wadsworth, 1989). As the child reaches eleven years of age and enters the 'formal operational stage', Piaget (1969) postulated that the child is able to progress from logical reasoning of concrete problems to logical reasoning to abstract and more complex problems. In contrast, a child pre-concrete operational stage accepts rules and values by those they perceive to be in authority, for example parents, teachers and health care professionals (Wadsworth, 1989). The application of Piaget's theory suggests it is unlikely that children less than eleven years of age are able to participate fully within the decision-making process of their asthma management, although self-management begins to develop. A limitation of Piaget's theory of cognitive development is lack of acknowledgement of the social construction of childhood, children's agency or rights and it has been suggested Piaget views children as '*less than fully human, unfinished or incomplete*' (Jenks, 1996: p. 10). Further criticism highlights the lack of appreciation of environmental and contextual factors that may account for variations in the individual child's development

(Furth and Youness, 2000). A child aged seven to eleven develops more complex cause and effect relationships and although may not associate that a cold environment can trigger an asthma attack, through experience these types of causal relationships evolve (Borzekowski, 2009; Carlson *et al.*, 2004).

Asthma symptoms present with behavioural and visual cues including breathing difficulties and/or coughing (Welch, 2000); anxiousness or restlessness (Beers, 2003); and as a late consequence in severe acute episodes significant hypoxemia results in cyanosis, lethargy and confusion (Beers, 2003). The UK has the highest rates for unnecessary deaths in children less than 14 years of age (Royal College of Paediatrics and Child Health, 2013); five children die each day unnecessarily from asthma, meningitis and pneumonia (Roberts and Campbell, 2013). Reports of children dying from an acute asthma episode at schools have been attributed to lack of workable asthma policies and insufficient training of school staff, including teachers (Hull, 2010). The implementation of government documents (DH, 2007; DfES/DH, 2005; 2004a; 2004b; DH, 2001) as highlighted in Chapter 1, Section 1.2 does not appear to be embedded into practice and there is a lack of skills amongst teachers when responding to a child which has an acute asthma episode. Although children may understand the meaning of asthma and recognise acute symptoms they may not have the cognitive reasoning abilities to manage the complexity of relationships with school staff and teachers; illustrating the importance of children's agency.

Children's health is placed as a priority amongst the healthcare agenda and implores that every organisation works together to improve children's health (Roberts and Campbell, 2013); allowing for children to demonstrate their agency does not appear a priority. A lack of an individual care plan in school is a contributing risk factor of an acute asthma episode and yet only 3% of children have an individual care plan in school (Roberts and Campbell, 2013). When working as a school nurse within a large local high school, only four teachers attended a training session on how to use an epipen, essential to respond to a child experiencing an allergic reaction. At the time, nine children within the high school had epipens, illustrating the need for the research to raise the visibility and increase people's values on children's health. In relation to asthma it has been suggested that training teachers to respond to an acute asthma episode should be mandatory (Hull, 2010). Five preventable child deaths occur

within the UK on a daily basis as child health is in crisis (Royal College of Paediatrics, 2013). Children can become ill and deteriorate quickly but also recover quickly and involving the child within the management of long-term conditions, such as asthma, enables them to be better informed to act on their symptoms when their parent is not present.

Contemporary sociology has emphasised the social construction of childhood over the last two decades (Mayall, 2012); and although research is beginning to respond to the concept of children's agency, a gap remains between the theory, policy and practice (Tisdall and Punch, 2012; Percy Smith and Thomas, 2010). Health services are failing to embed constructs of the child as an agent into service delivery, which is particularly salient for children with a long-term condition such as asthma, where self-management is essential for health and well-being (Laurance, 2013). This study explores children's agency and the gap between theory and practice. If the child has the knowledge and skills to recognise the early signs of an acute asthma episode then the likelihood of successful treatment is increased (Meng and McConnell, 2002). Subsequent control of asthma symptoms requires the child to acquire the necessary cognitive and behavioural skills to interpret a physical symptom long before there are any visual clues of an asthma exacerbation. Piaget's theory (1969) offers detailed behavioural descriptors, however it does not offer an explanatory account of children's thinking or allow for children's understanding or acknowledgement of early warning signs in the context of asthma. It suggests children could not attain certain concepts until they reach the appropriate age related cognitive development stage (Piaget, 1969), although the way children learn and behave being dependent on age, has not been confirmed (Field, 1987; Halford, 1982). Despite limitations, Piaget's (1969) theory is widely recognised and has been useful to inform study findings in relation to the child's ability to participate in the decision-making process.

Piaget (1969) suggests that children of seven to eleven year age have to rely on their parent to interpret their experience of asthma; whereas Vygotsky's (1979) theory suggests and observed in clinical practice, that children in this age range are able to self-manage their asthma. The importance of the child's experiences in relation to social interactions was identified as the main determinant of a child's cognitive development (Tudge and Rogoff, 1999). Vygotsky (1978) postulated that a child's cognitive development can be thought of in



terms of actual and potential development, which he labelled the '*zone of proximal development*'. Further studies have confirmed that children have the capacity to solve problems beyond their current capabilities which can be achieved with interaction and support from a competent adult (Borzekowski, 2009; Rogoff, 2003, 1990; Vygotsky, 1979). Consequently the child is likely to be receptive to being actively involved in the management of their asthma, even from a young age (Borzekowski, 2009; Vygotsky, 1979). The expertise of the person interacting with the child can positively impact on the child's cognitive development (Rogoff, 2003, 1990). As the child's skills, knowledge, understanding and confidence for the asthma management increases the adult can decrease their control (Vygotsky, 1978).

Children seven to eleven years of age are involved in the decision-making process for their asthma management, consistent with the notion of children as having agency (Mayall, 2002). A child demonstrates agency by '*actively taking control, by taking charge and having a direct effect on their situation*' (John, 2003:p195). Children's agency is most often applied in the contexts of the '*participation*' and '*rights*' of children (Valentine, 2009:p347) and begins in infancy when a baby cries to be fed or the avoidance of unpleasant stimuli (Alderson *et al.*, 2005). Agency, in the context of a child with asthma, recognises the child is not a passive recipient for their asthma management but an active participant within their world and capable of making decisions about issues that relate to them, understanding their actions have consequences (Hedges, 2012; James, 2007; Mayall, 2002).

Children make up 40% of the world population and within the UK it has been reported that '*children have been denied the learning experiences which are fundamental to the development of a sense of personal autonomy*' (John, 1995: p122). Children's agency appears key to the inclusion of the child, but children may not always desire to demonstrate agency in their asthma management (John, 2003). 'Thick' and 'thin' agency can be applied to explain the differing levels of agency within different contexts '*thin agency refers to decisions and everyday actions that are carried out within highly restrictive contexts, characterised by few viable options. Thick agency is having the latitude to act within a broad range of options. It is possible for a person's agency to be thickened or thinned...contexts and relationships can act as thickeners or thinners of an individual's agency*' (Klocker, 2007; p85). Sharing decisions

may enable the child to demonstrate 'thick' or 'thin' agency, without exerting too much pressure on them (Tisdall and Punch, 2012; Klocker, 2007; p85).

Research suggests that children five years to eleven years of age have the cognitive ability to understand and implement preventive health actions needed for the management of their asthma (Watts, 2008; Welch, 2000). According to Vygostky's (1978) theory providing children with adult support, to master problems beyond their current capabilities, enables children successfully to self-manage their asthma. Developing the skills to self-manage their condition is particularly relevant in situations where a parent is not present - such as at school and leisure activities (Buford, 2004; Callery, 2003). Child-parent collaboration has the potential to foster empowerment for the child to manage their asthma and reduce the impact on daily life. The cognitive theories have been drawn on to help explain how children manage their condition in the absence of parents, the relationship between child-parent decision-making process and child's health behaviours. Cognitive theorists are not the only perspectives to consider, learning theorists (Bandura 1989, 1986, 1977; Rotter 1966) offer an alternative view point.

### **2.2.2 *Learning theories***

Learning theorists argue that learning experiences develop a child's cognitive abilities. Bandura's (1989, 1986) theory is one of the most widely referred to learning theories, which expanded his initial work on social learning theory. In addition to learning through direct reinforcement, children also learn through the observation of others. The extent that children learn from observing others depends on four factors: what the child observes; what the child is able to copy; what the child can remember; and what the child wants to replicate (Bandura, 1989). Therefore, participating within the decision-making process will facilitate the child's learning of managing their asthma. The child's self-efficacy belief is pivotal in their ability to be involved and contribute within the decision-making process of the management tasks of the long-term condition (Schwarzer, 2008).

Self-efficacy belief introduced by Bandura (1977) refers to the child's belief or confidence in his/her own competence in accomplishing new roles and responsibilities. A low self-efficacy

acts as a barrier to the behaviour-environment interactions, whereas high self-efficacy enables a more favourable behaviour-environment interaction and challenging goals set by the child (Bandura, 1977). Self-efficacy is not a fixed trait and varies across situations; which may explain variability in the level of child participation in decision-making across different contexts. The child displaying high self-efficacy during decision-making processes and performing asthma management behavioural tasks can be encouraged and re-indorsed through positive parental and professional feedback (Rollnick *et al.*, 2007). Episodes of high self-efficacy can be used to explore and utilise different approaches through the shared decision-making process to enhance the child's self-efficacy beliefs. Participation is the most effective way to increase self-efficacy belief, further highlighting the importance of involving the child in decisions about their asthma management, increasing the child's skills in self-management (Buford, 2004).

Self-efficacy theory has been used as the theoretical framework to explore parent and child perspectives on managing a childhood long-term condition (Milnes *et al.*, 2013; Kaul, 2010; Kratz *et al.*, 2009; Marks *et al.*, 2005). Children's self-reported findings in a descriptive correlational research study, demonstrated a positive significant relationship between the child's self-efficacy belief and the management behaviour of their asthma (Kaul, 2011). However, a further study reported a statistically significant difference between self-reported measures of self-efficacy belief and asthma management behaviour (van Staa, 2011). Therefore, self-efficacy beliefs alone cannot be used as a predictor of management behaviour (Milnes *et al.*, 2013; van Staa, 2011). Many other demographic and psychosocial variables affect a child's decision-making process: individual characteristics, interaction with adults, previous experiences, resources and support available (Burkhart and Rayens, 2005).

Although the self-efficacy belief of the child is an important factor in the decision-making process and asthma management behaviour, health locus of control has also been identified as an influential factor (Rotter, 1966). Allowing a child to participate within the decision-making process facilitates control over their asthma management (McPherson and Redsell, 2009). The child's ability to contribute towards decision-making will be dependent on their perceived loci of control (Rotter, 1966). A child with a strong internal locus of control

perceives success is dependent on their behaviour and will often work harder to manage their asthma, including the administration of preventative asthma medication (Burkhart and Rayens, 2005). Evidence indicates that children, up to the age of twelve, can be aware of asthma triggers but do not demonstrate any obvious signs of avoiding allergens (Buford, 2004), potentially influenced by a strong sense of external locus of control (O'Brien *et al.*, 1989). The health locus of control theory and self-efficacy belief model, are extremely useful to explain and understand the child's level of participation and their agency within the decision-making process. However, these theories neglect to address the family input within the decision-making process of managing a long-term condition.

### **2.3 Family response to child illness**

The cognitive learning and development of a child, their ability and confidence to manage their own health and their health beliefs are all influenced and linked by family, friends, teachers and social context in which their life operates. Relationships between such concepts become more complex when families response and adjustment to living with a child with a long-term condition, varies from good to poor (Hafetz and Miller, 2010; Kratz *et al.*, 2009; Austin *et al.*, 2008). A large longitudinal study of 224 children aged four to fourteen years with asthma and 104 of their parents identified an association between parental responses to the child's long-term condition and the child's immediate health outcome (Austin *et al.*, 2008). Parents shared concerns and fears about the impact of the condition on the child's health outcome, but concerns were reduced within the family environment, when parents encouraged child autonomy of the management of the long-term condition (Austin *et al.*, 2008). The health belief model, cognitive and learning theories do not account for the dynamic nature of the condition and the cumulative effect of different problems within an underlying background of a long-term condition. In addition, the role of family members in sharing decisions about the management of a child's long-term condition are not easily explained by the models outlined. Theories that begin to explain these differences: the transfer of asthma management responsibility from parents to their school-age child (Buford, 2004) and family systems theory (Bronfenbrenner, 1979) are explored.

### **2.3.1 *Parent-child transfer of asthma responsibility model***

The parent-child transfer of asthma responsibility model (Buford, 2004) was derived from a grounded theory study of 14 children aged between seven and thirteen years, with a diagnosis of asthma and at least one of their parents. The Buford model (2004) developed from both the parent and to a much lesser extent, the child's perspectives, describes the process of transfer of responsibility of asthma from the parent to their school-aged child. However the model does not explicitly examine the decision-making process between children and parents in relation to childhood asthma management. The research was dominated by parent narratives and does not include the notion of children's agency (Tisdall and Punch, 2012). Although, the findings were consistent with a similar grounded theory study about parents' experiences of accommodating children's asthma (Jerrett and Costello, 1996); Buford (2004:p6) identifies three discrete states parents experience following their child being diagnosed with asthma, which are:

- Out of Control (which was associated with seeking help);
- Autopilot (integration of asthma management within family routine );
- Letting Go (child is competent within their asthma management).

In addition there are two transitional stages distinct from the three 'states', which were attributed to supporting the transfer of responsibility from the parent to the child (Buford, 2004; p6):

- Gaining Control (teaching the child to accept limitations and manage exacerbations);
- Empowerment (associated with the child demonstrating independence in self-managing their asthma).

Individual characteristics of the family, for example the parenting styles and the personality of the child, were observed to impact and influence each of the phases of the model (Buford 2004; Maccoby and Martin, 1983; Baumrind, 1967). However the process of transfer of responsibility and links between phases was not adequately described. For example, factors that facilitate the transitional period from parent management to child management include: parents' perceptions of the benefits of transferring responsibility; children's

perceptions of the benefits; and the available physical, social and psychological resources to support transfer of responsibility (Williams *et al.*, 2007).

A range of strategies have been untied to enhance transition of care from parent to child period including: involving re-educating the child on the disease management (Buford, 2004); progressing to close supervision (Buford, 2004); following this with a decreased supervision time allowing the child greater responsibility (Modi *et al.*, 2008). This is compatible with Vygotsky's theory of reducing the parental support when the child has accomplished the new task. However the stages within Buford's (2004) model are similar to Piaget's cognitive development and the age related changes affecting the child's participation within the decision-making process. The parent appears to control the transfer of the asthma management to the child. Specific cues observed by the parent initiate the transition (Buford, 2004). These clues include: *'developmental changes, anticipated and actual separations, initiative shown by the child to assume more responsibility, health care provider advice'* (Buford, 2004:p11). Children know more than they understand and demonstration of that knowledge is often context specific, explaining the lack of consistency between solving problems in different situations (Buford, 2004); explaining why their self-efficacy belief on self-managing their asthma may change. The empowerment 'state' appears to be the only 'state' to acknowledge the recognition of children's agency and the child's developing independence in their decision-making for asthma management. The empowerment 'state' incorporates the child's response to asthma symptoms; self-treatment decisions of asthma symptoms; aware of specific triggers for their asthma and steps to minimise the triggers; responsibility for decision to take preventative inhaler (Buford, 2004). The transfer of asthma management responsibility from parents to their school aged children appears to be a parent dominated model with little recognition of the child's voice. Although the model is limited in perspective, it does provide a good platform from which to examine other theories, certainly from a more child focussed perspective.

### **2.3.2 Family systems theory**

Family systems theory has relevance for explaining how children and parents manage the child's asthma in relation to boundaries, controls and hierarchies within which the family

operates; consequently shaping the short and long term health of the child (Bronfenbrenner, 1979). In addition a holistic understanding of the family and functions is required to understand the decision-making process for the management of a child's long-term condition. The child's development is facilitated by protecting the child from harm whilst enabling the child to explore the wider environment (Bronfenbrenner, 1979). Family systems theory (Bronfenbrenner, 1979) is based on a dynamic relationship between three interlinked layers:

- the innermost layer, the 'microsystem', relates to the child's everyday experiences such as family and school;
- the surrounding layer, 'exosystem' consist of aspects of the environment that influence the development of the child indirectly, for example parents' work or parents' friends;
- the outer layer, 'macrosystem' encapsulates the whole system and consists of aspects of the sub cultural setting, such as the ethnicity of the family, the family income or the environment.

These external and internal forces are likely to impact on the child and parent's decision-making in relation to the management of the child's asthma. The support provided by a parent, teacher or peer can influence a child's learning and confidence in the ability to cope with asthma management tasks. Halterman *et al.* (2000) identified that noncompliance with prophylactic medication led to an overuse of reliever medication by both parents and children in the presence of asthma symptoms. Consequently resulting in an increased risk of side effects and wastage of resources including: the prescribed medication; increased emergency visits; and missed time from school or work if parents take time off work to care for their child (Dinwiddie and Müller, 2002).

Research highlights that mothers predominantly are responsible for the daily management of the child's asthma and in emergency situations, traditionally undertaking more parenting care than men, particularly in the context of managing a child with a long-term condition (Dickinson and Dignam, 2002; Markson and Fiese, 2000; Williams, 1999; Ribbens, 1994).

Children often view their mother as their primary carer (Mayall, 2002). In addition, mothers perceive that they have sole responsibility for their child, which may provide friction between the child and the mother during the transitional stage of children becoming the primary manager of their asthma (May 2008; Duncan, 2005; Buford 2004). There is growing evidence that father's perception of living with a child with a long-term condition may offer a broader insight into the decision-making process within the family environment (Cashin *et al.*, 2008; Sullivan-Bolyai *et al.*, 2006; Goble, 2004; Hovey, 2003). The mother's coping styles and quality of life has also been identified as having a significant impact on the child's ability to cope (Sales *et al.*, 2008; Marsac *et al.*, 2006). Mothers can be overprotective, limit the amount of control within the decision-making the child is able to exhibit; seen more so with sons than daughters (Williams, 1999).

Children with moderate asthma and their families learn to live with their long-term condition (Prout *et al.*, 1999; Frank, 1995). A qualitative study conducted by Prout *et al.* (1999), explored several management strategies implemented by families whose child had moderate asthma symptoms, indicating administration of medication being the most prevalent. The families administer the medication, usually an inhaler, to facilitate the effective management of the asthma and increase the child's feeling of 'ordinariness' amongst their peers. Children and mothers express the emotions of fear, anxiety and anger in the initial stages preceding an asthma attack (Gabe *et al.*, 2002; Callery *et al.*, 2003). Whilst these feelings are thought to decrease as they gain more control in their decisions and learn how to manage their own asthma more effectively, some young people indicated the fear and panic never diminish (Gabe *et al.*, 2002).

### **2.3.3 Parenting Styles**

Exploring the parenting style enables an understanding of how the family operationalise asthma management decisions. Parents usually display one of four parenting styles: 'Authoritarian Parenting', 'Authoritative Parenting', 'Permissive Parenting' and 'Uninvolved Parenting' (Maccoby and Martin, 1983:p39-49; Baumrind, 1967:p44). Each of the four approaches are explained:

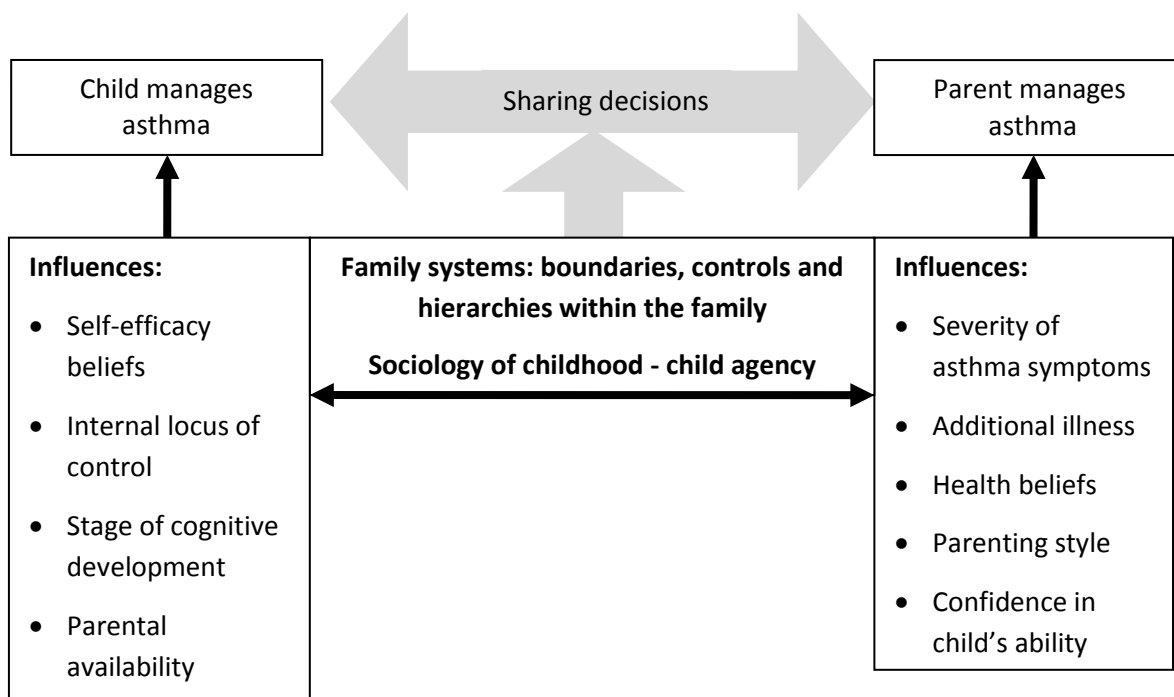


- Authoritarian Parenting is concerned with the expectation of the child complying with the strict decisions established by the parent. Usually there is no reasoning behind the decisions implemented by the parent. These parents typically have high expectations of their child and punish if their child does not comply with rules and decisions. These children tend to be proficient but low self-esteem. In relation to the findings of this study, the parent decision preferences will over-ride the child's decision preferences.
- Authoritative Parenting is concerned with a similar concept to Authoritarian Parenting but is much more democratic. These parents typically expect the same high standards from their child but will offer reasoning behind the strict decisions and rules. If the child is unable to achieve the high standards, the parents are usually more nurturing and more forgiving than in Authoritarian Parenting. This type of parenting tends to result in a happier, more capable child. In relation to the findings of this study, the parent decision preferences are still likely to dominate the child's decision preferences but will allow a child to express a view within the decision-making process.
- Permissive Parenting is concerned with a parent making few demands on their child. The relationship is more 'friends' than 'child-parent'. However, this type of parenting typically has low expectations of their child. Parents typically allow their child to make decisions. These children tend to perform poorly in school and have difficulties with discipline in school. In relation to the study findings within this thesis, the child will have autonomy over the decision-making process but this does not necessarily reflect the child's decision preference.
- Uninvolved Parenting is concerned with a parent meeting the child's basic needs but with little interaction and communication with a general detachment from decisions within their child's life. These children tend to have low self-esteem and less competence than their peers. In relation to the study within this thesis, irrespective of the child's decision preferences, is forced into autonomous management decision-making with little or no participation from their parent.

## 2.4 Conceptual framework

The interplay between the theoretical perspectives outlined have been synthesised into a conceptual framework as a means of bringing together concepts relating to child-parent decision-making in the context of living with a child with a long-term condition such as asthma (Figure 2). The conceptual framework has been used to guide the structured literature review presented in Chapter 3 and the methods associated with this study undertaken as part of this thesis, outlined in Chapter 4.

**Figure 2: Conceptual framework of child-parent shared decision-making**



## 2.5 Summary

This chapter has presented a range of theories and concepts that assist in explaining the factors that influence child-parent decision-making and the transitional process of the child taking responsibility for their asthma management. However, the cognitive development theories fail to address the collaborative nature of the management decisions between child

and parent, incorporated within Buford's theoretical model of transfer of asthma management responsibility from parents to their school-aged children. Buford's theory (2004) has direct relevance to the present study of child-parent decision-making and has been explored to help explain the findings of the study. Piaget's theory (1969) provides some understanding of a child's cognitive development through assimilation and accommodation. Whereas, Donaldson (1978) expands on Piaget's theory claiming that Piaget put a ceiling on a child's level of thinking and underestimated a young child's abilities. Vygotsky (1978) on the other hand argues adults can support a child's learning to achieve a higher cognitive level through assisted learning. Juxtaposing Piaget, Donaldson and Vygotsky with Buford suggests a higher potential of what a child is able to achieve through participating within the decision-making for their asthma management. The critical review of the theories and concepts that relate to child-parent decision-making for asthma management have been brought together to form a conceptual framework that informs the study.

The next chapter presents the findings from a structured literature review of research relating to child-parent decision-making of the management of childhood long-term conditions to contextualise the study aims and objectives and explore the gaps in the current research evidence.

**Child-parent shared decision-making: critical review of the literature**

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**3. Introduction**

This chapter presents a critical review of current research findings relating to child-parent shared decision-making for the management of childhood long-term conditions. A long-term condition is a permanent health condition that affects the child's growth and development; requiring ongoing health support for the child and family (Stein and Silver, 1999). An initial scoping review suggested a paucity of research relating to child-parent shared decision-making in the context of asthma. Therefore a wider structured literature review was undertaken focusing on child-parent shared decision-making across a range of long-term conditions in childhood. As the majority of care decisions for the management of childhood long-term conditions occur within the home (Kieckhefer, 2009; Kratz *et al.*, 2009; Ray, 2002), it is likely similarities exist across different conditions. The review findings will be drawn on, along with the conceptual framework developed in Chapter 2, to explain and contextualise the findings of the study.

**3.1 Review context**

Reviews of research are undertaken for a range of reasons including: ascertaining the contribution other researchers have made to the field of study; identifying and critically analysing relevant literature; demonstrate where knowledge is lacking; and to provide an evidence-base for practice that can inform policy makers, professionals and patients when making healthcare decisions (Brewer, 2007). The objective of this review was to identify and critically analyse research relating to child-parent shared decision-making for long-term conditions, prior to undertaking research in a related area, therefore a structured review was undertaken (January 2000 – February 2014), using systematic methods in accordance with the United Kingdom Centre for Reviews and Dissemination guidance (CRD, 2009).

Types of review designs include: scoping, narrative, structured and systematic reviews.

Scoping reviews provide an overview of the range and depth of related research, without a detailed analysis of identified research and may be used to map existing literature in isolation or prior to undertaking a systematic review. Quality assessment is not normally undertaken in scoping reviews, limiting their usefulness to inform practice (Grant and Booth, 2009). Narrative reviews critique and summarise relevant literature but the criteria for selecting papers to review is not always transparent (Cronin *et al.*, 2008) and are often perceived as lacking rigour because typically a limited selection of research is included which can result in author bias (Grant and Booth, 2009).

Structured reviews are used to summarise and synthesise research findings within the constraints of a given timetable and resources and as in this review, to contextualise primary studies prior to undertaking research in a related area (Armitage and Keeble-Ramsay, 2009; Armitage and Keeble-Allen, 2008). Although a systematic review attempts to incorporate all the published and unpublished studies relating to a specific topic, they are time consuming and labour intensive with high cost implications and outside the scope of most research (Clark and Thapa, 2011; Cronin *et al.*, 2008; Timmins and McCabe, 2005), including the research undertaken as part of this PhD. A structured review was employed to identify and critically analyse primary research studies that has explored child-parent shared decision-making in the context of children living with a long-term condition. The methods used to conduct the review were informed by guidance from the United Kingdom Centre for Reviews and Dissemination guidance (CRD, 2009).

### **3.2 Aims and objectives**

The review aimed to explore child-parent shared decision-making in the management of a long-term condition in childhood.

The specific objectives were to:

1. Identify and summarise research that has explored child-parent shared decision-making in the context of children living with a long-term condition;

2. Describe and explore the key barriers and facilitators that hinder or enable child-parent shared decision-making in the context of children living with a long-term condition;
3. Identify decision-making theories or frameworks that may be useful to guide practice in relation to supporting child-parent shared decision-making;
4. Explore how previous researchers, within this topic area, have designed studies.

### **3.3 Critical appraisal**

All study designs were included in the structured review of the child and/or parent perspective of shared decision-making for the management of a long-term condition. Primary research studies were included if they met the following inclusion and exclusion criteria:

- Child and/or parent perspective of living with a child, with a long-term condition;
- Concerned with a child who has a long-term condition;
- Where the research focus is child and parent shared/collaborative/partnership decision-making;
- Relating to child and parent management decisions about the child's illness;
- Decision-making in relation to maintaining treatment;
- Seeking health care advice and support;
- Involving children aged seven to eleven years.

Articles were excluded based on the following exclusion criteria:

- Not published in the English language;
- Not focussed on decision-making;
- Where the decision-making is not about health related issues;
- Review articles

### 3.3.1 *Sampling strategies*

A range of key bibliographic databases, Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Science Direct and Web of Knowledge were searched. These databases were selected because they routinely index a wide range in health related subject matter from health and social sciences journals (Cronin *et al.*, 2008). Medline database is widely recognised as the gold standard for bibliographic and abstract literature on biomedicine but also includes publications related to allied health care professionals, biological and physical sciences relating to medicine and health care. CINAHL database is the authoritative resource for nursing and allied health care professionals, indexing over 1200 nursing journals. PsycINFO database covers the professional and academic literature in psychology and related disciplines; including nursing. Science Direct database offers over 25% of the world's medicine full text.

Web of Knowledge database offers bibliographic content to access, manage and analyse social science research. Bibliographies of key papers were also reviewed to identify any additional papers (Ely and Scott, 2007). The period January 2000 to February 2014 was chosen due to changes in health policy in the 21<sup>st</sup> century with greater emphasis on patient and family centred care and the inclusion of the child's perspective in health care decisions (DfES/DH, 2004a; 2004b; Dixon-Woods *et al.*, 1999). Boolean operators, 'AND', 'OR', 'NOT' were used to combine sets of searches (Caldwell *et al.*, 2012; Cronin *et al.*, 2008); MeSH terms, allow for the subject headings to range from broader to narrower (Caldwell *et al.*, 2012); and truncation ('\$' or '\*') were used to produce a more focussed search result (Cronin *et al.*, 2008). For example, child\* will retrieve child, child's, children and children's. Key search terms and search strategy for Medline are presented in Table 1 and Appendix 1, respectively. These terms were adapted across databases. For example, the American database CINAHL may not have recognised the British spelling of paediatric therefore the term pediatric was substituted, to elicit the relevant research (Younger, 2004).

**Table 1: Key search terms**

Population 1	Population 2	Focus	Theoretical concepts
Parent/s Mother/s Father/s Carer/s Guardian/s Foster carer/s Grandparent/s	Child Children Pediatric/s (US) Paediatrics (UK) Daughter/s Son/s	Long-term illness Chronic disease Chronic illness Chronic condition Long-term condition	Shared decision-making Partnership Collaboration

Abstracts were evaluated for their suitability for inclusion in the review using a screening tool (Table 2). The development of a data extraction form (Appendix 2) enabled similar data to be extracted from each article, reducing bias and facilitating comparative analysis of findings (CRD, 2009).

**Table 2: Screening Tool**

Screening tool Inclusion and Exclusion Criteria			
	Inclusion Criteria	Yes	No
1	Participants are child and/or parent/s		
2	Child has long-term condition		
3	Involving a child between seven and eleven years of age		
4	Research focus is child and parent/carer shared decision-making, collaboration, partnership		
5	Research related to decisions about child's illness		
6	Decision-making in relation to maintain treatment and care plans		
7	Decisions about managing potential triggers that may exacerbate the long-term illness		
8	Decisions about seeking health care advice and support		
	<b>Exclusion Criteria</b>		
9	Not published in English language		
10	Not focussed on decision-making		
11	Decision-making is not about health conditions similar to asthma		
12	Review papers		

If the reviewer is able to provide a favourable response to items one to five and either six, seven or eight from within the inclusion criteria the abstract was included within the review.



If however, the abstract relates to item nine, ten, eleven or twelve within the exclusion criteria, it was rejected.

### **3.3.2 Critical appraisal tools**

A systematic review of critical appraisal tools identified over 100 tools for appraising research including tools suitable for systematic reviews (n=26), experimental studies (n=45), diagnostic studies (n=7); observational studies (n=19), qualitative studies (7), experimental and observational studies (n=6) and other designs (n=10) (Katrak *et al.*, 2004). The majority of the appraisal tools used were developed for use on empirical research with the remainder suitable for reviewing systematic reviews (Katrak *et al.*, 2004). The findings of the review did not identify a 'gold-standard' assessment tool for each study design (Katrak *et al.*, 2004). Of the seven assessment tools identified for qualitative studies, the Critical Skills Appraisal Programme (CASP, 1998) tool was highlighted as particularly useful to systematically examine the trustworthiness, value and relevance of the qualitative research study because of ease of use and the clarity of explanations for each of the ten assessments criteria.

Studies included in this review, with three exceptions (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009), employed qualitative methodology. Therefore the CASP assessment tool template was used to appraise these studies (Appendix 3). The Health Care Practice Research and Development Unit evaluation tools (Appendix 4) (Long *et al.*, 2002a; Long *et al.*, 2002b) was used respectively, for the quality appraisal of the quantitative study (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009) and mixed-methods study (Newbould *et al.*, 2008; Miller *et al.*, 2008). The first two items of the CASP tool are screening questions to ascertain whether it was worth the researcher pursuing the study. If the reviewer is able to provide a favourable response to the screening questions, the remaining eight detailed questions were applied to each qualitative study. The assessment tool was changed and adapted to meet the needs of child-parent shared decision-making for the management of a long-term condition. For example, the first screening question asks 'was there a clear statement of the aims of the research?' In the context of the structured review the aim of the research needs to involve decision-making between the child and parent for the management of a long-term condition. The screening questions and detailed questions are summarised in Table 3.

**Table 3: Summary of CASP assessment tool (CASP, 1998)**

	Assessment criteria
<b>Screening questions</b>	1. Was there a clear statement of the aims of the research?
	2. Is a qualitative methodology appropriate?
<b>Is it worth continuing?</b>	
<b>Detailed questions</b>	3. Were recruitment strategy appropriate to the aims of the research?
	4. Were the data collected in a way that addressed the research issue?
	5. Was the data analysis sufficiently rigorous?
	6. Has researcher-participant relationships been adequately considered?
	7. Are the findings clear?
	8. Is sufficient data represented to justify researcher interpretations?
	9. Has the transferability to other settings been made explicit?
	10. How relevant is the research?

### **3.3.3 Identifying themes from the data**

The primary objective of the review was to identify and summarise research that explored child-parent shared decision-making in the context of children living with a long-term condition. Therefore, the principles of thematic analysis underpinned the data analysis throughout the review of the qualitative studies (Thomas and Harden, 2007; Braun and Clarke, 2006). The stages of thematic analysis include familiarisation of the data; generating codes; searching for themes; defining themes; reviewing; and describing final themes of the phenomenon being studied (Tesch, 1990). Due to the small number of quantitative studies included and their diversity, statistical analysis was not undertaken but themes were identified and incorporated into the review findings.

### **3.4 Procedures**

This section will describe the procedures undertaken for the selection of papers, data extraction, quality appraisal procedure for each paper and the overview of review studies.

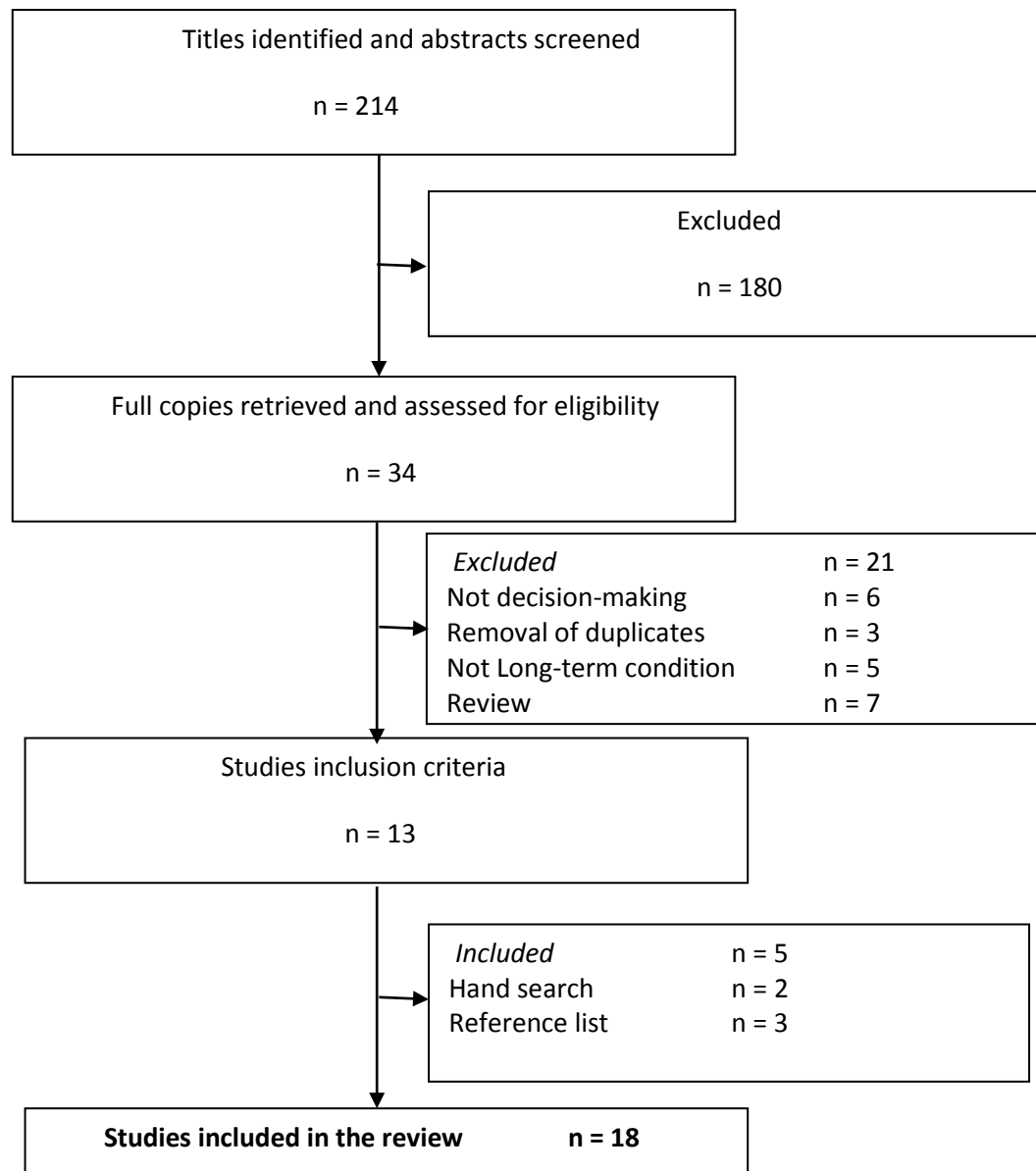
#### **3.4.1 Selection of papers**

The electronic databases yielded a total of 214 possible articles that met the inclusion criterion. Article selection followed the guidelines within the CRD healthcare review guide (CRD, 2009). The title and abstract of each article was examined to ascertain if it related to the focus of the review. Thirty four abstracts related to the focus of the review, full papers were retrieved and assessed for eligibility against the inclusion criteria. Thirteen papers met the inclusion criteria. Twenty one papers were excluded as they either did not focus on shared decision-making (n=6); or the decision-making was not about management of long-term conditions similar to childhood asthma (n=5). Conditions included pain management, cleft palate surgery, palliative care and eating disorders; review papers (n=7); duplicate papers (3). A hand search identified an additional two papers; a further three papers were identified from the references of included papers, resulting in eighteen papers being included in the review (Figure 3).

#### **3.4.2 Quality appraisal**

Quality appraisal for each study was undertaken by assessing the research against the predetermined criteria within the CASP tool as outlined in Table 3, Section 3.3.2. and the HCPRDU tool (Appendix 4). The CASP tool does not attach scores to each criteria, instead each criteria item was scored 'yes' if the criteria were fully met; 'no' if none were met; and 'partial' if the criteria were partially met. For example item two of the CASP assessment tool evaluates if a qualitative methodology is appropriate to address the research aims. In Newbould *et al.*'s (2008) study employing a qualitative approach was justified to facilitate the child to express their views on partnerships between themselves and their parents in the management of medication for asthma and diabetes and scored 'yes'.

**Figure 3: Flow chart of study selection process**



Item five within the CASP assessment tool evaluates whether data were collected in a way that addressed the research issue. An example of how this was achieved is highlighted in Miller's (2009) study, using both focus groups and individual interviews, to elicit data collection methods was justified as a means of enabling participants to discuss similarities and differences in their experiences of child-parent decision-making for the management of long-term conditions. Although this shared understanding could be gained through a focus

group, some children, due to the nature of their condition (cystic fibrosis required minimal group contact) necessitated using individual interviews.

Focus groups and individual interviews are both appropriate methods to elicit data collection from a child aged seven to eleven years (Fraser *et al.*, 2007; Mauthner, 1997). An example of where criteria were only partially met is demonstrated in Meng and McConnell's study (2002). Focus groups were used to elicit data from 28 school aged children and their parents on how treatment-related decisions are made. The six themes: worries; asthma knowledge; school issues; medications; parental support; and desire to be normal, are presented with limited interpretation of data findings (Meng and McConnell, 2002).

### **3.4.3 Data abstraction and identifying themes**

Data abstraction involved three phases:

1. Identification and documentation of information to meet the review aims and objectives;
2. Summarising study designs, methods and participants;
3. Developing categories and themes.

Identifying themes from the data involved reading each study, then summarising the categories, themes, concepts and metaphors used to describe the study findings (Thomas and Harden, 2008; Braun and Clark, 2006). Examples of salient data extracts were also used in the development of themes. Codes were summarised and recorded on a data extraction form in order to identify patterns across studies.

Similar codes were grouped together into broad categories. This was an iterative process, new categories were developed or existing categories modified as the review progressed (Thomas and Harden, 2008; Braun and Clark, 2006). An example of how a theme and related categories were developed for the theme labelled 'child-parent shared decision-making facilitators' is presented in Table 4.

**Table 4: Developing categories and themes from coded data**

Author	Code	Categories	Theme
Meng & McConnell 2002	Symptoms experienced by the child were the driving force for children’s participation in decisions	Child’s internal locus of control	<b>Facilitators of child-parent shared decision-making</b>
Fereday 2009	‘I just put my mind to it and I can do anything’		
Meah <i>et al.</i> , 2009	Relationship between chronological age and increased responsibility	Child’s cognitive development	
Buford 2004	Child developmental changes prompt mothers to encourage greater child responsibility		
Newbould <i>et al.</i> , 2008	Cognitive development influences transfer of responsibility of decision-making		

The following section presents an overview of finding from studies reviewed, including a summary of the quality appraisal assessment and the themes and categories that emerged from the synthesised findings.

#### **3.4.4 Overview of review studies**

A total of 18 studies were included in the review. A summary of the study characteristics relating to geographical location, long-term health condition, theoretical underpinning and the limitations of the studies are presented in Table 5. A summary of study design, participants, analytical methods and key findings are presented in Table 6. Thirteen studies employed qualitative methods (Pritchard, 2012; Hafetz and Miller, 2010; Fereday *et al.*, 2009; Meah *et al.*, 2009; Miller, 2009; Taylor *et al.*, 2009; Cashin *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Meng and McConnell., 2002; Pradel *et al.*, 2001), three studies employed quantitative methods (Chisholm *et al.*, 2012; Miller and Harris, 2012; Kiechefer *et al.*, 2009) and two studies employed mixed-methods (Newbould *et al.*, 2008; Miller *et al.*, 2008). Two separate studies both reported twice but data analysis focussed on different aims (Hafetz and Miller, 2010; Miller, 2009; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b).

**Table 5: Summary of study characteristics**

Author	Title	Location	Long-term health condition	Theoretical underpinning
Alderson <i>et al</i> 2006a	Children as partners with adults in their medical care	UK	Type 1 diabetes	Piagetian theories of child development
Alderson <i>et al</i> 2006b	Children's competence to consent to medical treatment	UK	Type 1 diabetes	Piagetian theories of child development
Buford 2004	Transfer of asthma management responsibility from parents to their school-age children	USA	Asthma	Model for child-parent transfer of asthma responsibility
Cashin <i>et al</i> 2008	The Lived Experience of Fathers Who Have Children With Asthma: A Phenomenological Study	Canada	Asthma	None
Chisholm <i>et al</i> 2012	An exploratory study of positive and incongruent communication in young children with type 1 diabetes and their mothers	UK	Type 1 diabetes	None
Fereday <i>et al</i> 2009	"There's nothing I can't do- I just put my mind to anything and I can do it": a qualitative analysis of how children with chronic disease and their parents account for and manage physical activity	Australia	Asthma, diabetes, cystic fibrosis	None
Hafetz and Miller 2010	Child and parent perceptions of monitoring in chronic illness management: a qualitative study	USA	Asthma, cystic fibrosis, type 1 diabetes	None
Kieckhefer <i>et al</i> 2009	Measuring parent-child shared management of chronic illness	USA	Chronic condition	Self-efficacy scores
Meah <i>et al</i> 2009	Thinking 'taller': sharing responsibility in the everyday lives of children with asthma.	UK	Asthma	Changing models of responsibility (Heimer and Staffen,1998)
Meng and McConnell 2002	Decision-making in children with asthma and their parents	USA	Asthma	Locus of control Health beliefs
Miller <i>et al</i> 2008	Parent- Child Roles in Decision-Making about Medical Research	USA	Asthma, diabetes, epilepsy or no chronic condition	Child's cognitive development

Miller 2009	Child-parent collaborative decision-making for the management of chronic illness: a qualitative analysis	USA	Asthma, cystic fibrosis, diabetes	None
Miller and Harris 2012	Measuring Children's Decision-Making Involvement Regarding Chronic Illness Management	USA	Asthma, cystic fibrosis or diabetes	Child locus of control Decision-Making Involvement Scale (DMIS)
Newbould <i>et al</i> 2008	'I'm fine doing it on my own': partnerships between young people and their parents in the management of medication for asthma and diabetes	UK	Asthma and diabetes	None
Pradel <i>et al</i> 2001	Asthma self-management: the perspective of children	USA	Asthma	Cognitive theories Behavioural theories Health belief model
Pritchard 2012	Systematic ethnography of school-age children with bleeding disorders and other chronic illnesses: exploring children's perceptions of partnership roles in family-centred care of their chronic illness	Canada	Bleeding disorder or other chronic illness	None
Taylor <i>et al</i> 2009	Child involvement in the paediatric consultation: a qualitative study of children and carers' views	UK	Asthma, headaches, head injury, oncology, epilepsy, attention deficit disorder and cystic fibrosis	None
Williams <i>et al</i> 2007	From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis	UK	Cystic fibrosis	Health belief model



**Table 6: Summary of study design and key findings**

Author	Main Aim	Participants	Method/tools	Key findings
Alderson <i>et al</i> 2006a	Explore the views of children with type 1 diabetes about their condition and ways they share in managing their medical and health care with adults	24 children aged between 3 and 12 years with type 1 diabetes	Qualitative: Semi-structured interviews Data analysis method not stated	Children make decisions to balance their physiological and psychological health
Alderson <i>et al</i> 2006b	Explore if children are competent decision-makers in relation to providing informed consent to medical research	24 children aged between 3 and 12 years with type 1 diabetes	Qualitative: Semi-structured interviews Data analysis method not stated	Child decisions facilitated by: Sufficient comprehension Voluntary consent Autonomy Legal Capacity
Buford 2004	Explore the process of transfer of responsibility for asthma management from parents to their children	14 children aged between 8 and 13 years with asthma, 11 mothers, 2 fathers and 1 grandma	Grounded theory in-depth interviews with child and parents. Follow up telephone interviews to clarify response that arose during the data analysis, field notes and personal information form.	Decisions relate to the transfer for asthma management responsibility from parents to their school-aged children
Cashin <i>et al</i> 2008	Understand the needs and concerns of fathers who have children with asthma	8 fathers (age range 39 to 46 years) of children 7 - 11 years with asthma. All educated Caucasians of Western Europe descent	Hermeneutic phenomenology: Unstructured interviews.	Father decisions facilitated by: Feeling relief in knowing the diagnosis Learning the ropes to manage condition Being vigilant to illness symptoms Living with concerns is constant Being comfortable with asthma management
Chisholm <i>et al</i> 2012	To study positive and incongruent communication in young children with diabetes and their mothers	26 6-8 year old children with type 1 diabetes and their mothers	Quantitative: Telephone interviews and observation (video recorded) Blood glucose measurement Child-behaviour checklist- Parent report. Mother-child collaborative problem-solving activity.	Positive dyadic management decision communication resulted in better child adjustment and adherence outcomes.

Author	Main Aim	Participants	Method/tools	Key findings
Fereday <i>et al</i> 2009	To explore the parent and child's perceptions and experiences of living with a long-term condition and their participation in physical activity	25 children aged between 4 to 16 year old (n= 1 diabetes; n=6 asthma; n=5 cystic fibrosis) and their parents	Interpretive phenomenology: Focus groups, maps, photos and 'traffic light posters' for the children. The parents were interviewed separately.	Child decisions to participate within physical activity is facilitated through parental support
Hafetz and Miller 2010	To explore parent and child perceptions and reactions to the monitoring of the management of the long-term condition, asthma.	18 children aged between 8 to 17 years (n= 3 asthma; n=9 diabetes; n=6 cystic fibrosis) and 14 mothers and 2 fathers age 33 to 59 years, 88% were white.	Qualitative: Focus groups and individual interviews Thematic analysis	Managing a child's long-term illness can be challenging Parental monitoring and child disclosure of health related information can affect the decision-making
Kiechefer <i>et al</i> (2009)	To measure child-parent shared management of chronic illness	129 parents of children aged between 2 to 11 year old with a chronic condition	Quantitative: shared management scale Cronbach Alpha overall scale 0.91.	The parent-child management scale can be used by health care professionals to identify the levels of shared decision-making management for the chronic illness
Meah <i>et al</i> 2009	To explore negotiation of responsibilities for asthma self-care between a group of preadolescent children and their parents	18 children aged between 7 to 12 year old with asthma and their parents	Feminist epistemology Qualitative: Open ended conversational type interviews. Framework approach	Limitations on children's opportunities to exercise decision-making responsibilities. Parents requested assistance from health care professionals in managing the transition to autonomous decision-making in children
Meng and McConnell 2002	To learn how children with asthma and their parents make treatment related decisions	11 girls and 17 boys aged 7 to 12 years with moderate to severe asthma, 26 mothers and 2 fathers.	Qualitative: Focus groups. Six questions were designed for parent focus groups and similar items using developmentally appropriate words for the children's focus groups. Thematic analysis	Children base their decisions on: worries, asthma knowledge, school issues, parental support, medications, a desire to be normal Parents base their decisions on: school issues, nocturnal symptoms, early warning signs, triggers

Author	Main Aim	Participants	Method/tools	Key findings
Miller <i>et al</i> 2008	To understand how parents and children perceive their roles in decision-making about research participation	45 children aged 4 to 15 years with asthma, diabetes, epilepsy 15 mothers and 6 fathers, with an age range of 33 to 59 years, 57% held a college degree or above	Qualitative: Grounded theory : Semi-structured interviews Content Analysis Quantitative: Peabody Picture Vocabulary Test	Collaborative decision-making appeared to increase with cognitive development
Miller 2009	To explore child-parent collaborative decision-making for long-term illness management	18 children aged 8 to 19 years (n=6 cystic fibrosis; n=3 asthma; n=1 diabetes) and 14 mothers and 2 fathers age 33 to 59 years, 88% were white.	Qualitative: Focus groups and individual interviews Inductive: thematic analysis	Child-parent collaborative decision-making is an important precursor to the child's self-management of the long-term illness
Miller and Harris 2012	To develop a measure of decision-making involvement in children	226 Child-parent dyads (aged 8 to 19 years) with asthma, cystic fibrosis or type 1 diabetes	Quantitative: Survey Multivariate regression analyses	DMIS subscales were associated with: child age child locus of control family communication
Newbould <i>et al</i> 2008	Partnerships between parents and children in managing medication in a child with either asthma or diabetes	69 young people aged 8 to 15 years (n= 43 asthma; n=26 diabetes) and their parents (n=138)	Qualitative: Semi-structured interviews. Quantitative: Coding of data.	Children are more involved in day-to-day asthma treatment decisions than consultations with health care professionals
Pradel <i>et al</i> 2001	Explore the knowledge, perceptions and autonomy of children 7 – 12 years in the management of their asthma	32 children aged between 7 and 12 years with moderate to severe asthma	Qualitative: Open-ended drawing interview and semi-structured interviews. Content analysis of the drawings and interviews. Frequencies of each child's response was counted and compared by age group	Younger children make decisions regarding medication use by shape and colour. Rely on adults to manage their asthma management decisions. The older children used their medication independently sometimes sharing decisions with parents

Author	Main Aim	Participants	Method/tools	Key findings
Pritchard 2012	To explore children's perceptions of partnership roles in family-centred care of their chronic illness	8 children aged between 7 and 11 years with either a bleeding disorder (n = 4) or other chronic illness (n = 4)	Ethnographic Unstructured interviews Content analysis	How children perceive their participation within decision-making for their long-term condition
Taylor <i>et al</i> 2009	Investigate child/parent attitude towards child involvement in consultations	21 children aged 7 to 16 years (n=2 asthma; n=2 headaches; others include road traffic accidents, head injury, oncology, epilepsy, attention deficit disorder and cystic fibrosis) and 17 mothers and 5 fathers, 60% were white British	Qualitative: Semi-structured interviews Framework approach	Children to be involved in the health consultation and participate within decisions relating to their health
Williams <i>et al</i> 2007	How management responsibility is transferred from the adult to the child	32 children with cystic fibrosis aged between 7 – 17 years and 31 parents	Qualitative: In-depth interviews Framework approach	Child and parent perceived benefits of transferring responsibility Available physical, social and psychological resources available facilitate with the transfer of decision-making responsibility

Tables 7- 13 present an overview of the number of studies in relation to: the geographical location of the study; participant characteristics; the child's health condition; underpinning theoretical perspectives; study design. Table 7 indicates that the majority of included studies were undertaken in the USA and UK.

**Table 7: Geographical location of the studies (n = 18)**

Location	UK	Canada	USA	Australia
Number of studies	7	2	8	1

Table 8 and 9 present the study participants and the health conditions of the children respectively. Of ten of the studies where both parents were invited to participate, fathers were recruited in six studies, representing a third of the sample (Table 6). Parent participant details were provided in five of the studies. Parent's ages range from 33 to 59 years and were predominantly of Caucasian origin. The child's ages ranged from 2 to 19 years (Table 6), although the upper and lower age ranges are outside of the inclusion criteria used within the study as part of this thesis their data findings could not be extracted from the data set.

**Table 8: Study participants (n = 18)**

Participants	Child	Child and Parent	Parent
Number of studies	4	12	2

**Table 9: Health conditions of the child (n = 18)**

Health Conditions	Mixed conditions	Asthma	Diabetes	Cystic Fibrosis
Number of studies	9	5	3	1

Nine of the studies involve children with a range of long-term conditions: asthma, type 1 diabetes, cystic fibrosis, epilepsy and headaches. Two of the studies also included children with a haemorrhagic disorder (Pritchard, 2012) and oncology, head injury and attention

deficit disorder (Taylor *et al.*, 2009). In one study some of the children did not have a long-term condition but was included because the main focus was to understand child-parent roles in decision-making about medical research (Miller *et al.*, 2008). In addition the reviewed study (Miller *et al.*, 2008) explored child-parent shared decision-making of the daily management of a childhood long-term condition. Participants included 45 children aged between four and fifteen years with asthma, diabetes, epilepsy or no chronic condition (Miller *et al.*, 2008). Within the reviewed studies sample sizes ranged from 8 to 226 participants. Qualitative samples are usually small but the information obtained is rich in detail (Ritchie and Lewis, 2004). The study with a sample size of 226 was a quantitative study using multivariate regression analyses to develop a measure of the child's involvement in decision-making regarding chronic illness management (Miller and Harris, 2012).

Table 10 presents the study design and methods. Six theories/models were employed across ten studies (Miller and Harris, 2012; Meah *et al.*, 2009; Kieckhefer *et al.*, 2009; Miller *et al.*, 2008; Williams *et al.*, 2007; Anderson *et al.*, 2006a; Anderson *et al.*, 2006b; Buford, 2004; Meng and McConnell, 2002; Pradel *et al.*, 2001), with three studies adopting more than one theoretical framework to underpin the research (Miller and Harris, 2012; Meng and McConnell, 2002; Pradel *et al.*, 2001). Eight of the studies appeared to have no explicit theoretical theory underpinning the research (Pritchard, 2012; Chisholm *et al.*, 2012; Hafetz and Miller, 2010; Fereday *et al.*, 2009; Miller, 2009; Taylor *et al.*, 2009; Newbould *et al.*, 2008; Cashin *et al.*, 2008).

Eleven studies used a descriptive qualitative approach (Hafetz and Miller, 2010; Meah *et al.*, 2009; Miller, 2009; Taylor *et al.*, 2009; Newbould *et al.*, 2008; Miller *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Meng and McConnell, 2002; Pradel *et al.*, 2001), one grounded theory (Buford, 2004), two phenomenology (Fereday *et al.*, 2009; Cashin *et al.*, 2008), one ethnography (Pritchard, 2012) and four studies used a quantitative study design (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009; Newbould *et al.*, 2008; Miller *et al.*, 2008). Interviewing was used to collect data in 12 reviewed studies (Pritchard, 2012; Chisholm *et al.*, 2012; Meah *et al.*, 2009; Taylor *et al.*, 2009; Fereday *et al.*, 2009; Newbould *et al.*, 2008; Miller *et al.*, 2008; Cashin *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Pradel *et*

*al.*, 2001). One study used focus groups to collect data (Meng and McConnell, 2002), three studies used both focus groups and interviews to collect data (Hafetz and Miller, 2010; Fereday *et al.*, 2009; Miller, 2009) and two survey designs (Miller and Harris, 2012; Kieckhefer *et al.*, 2009). Purposive sampling strategies were predominant across studies, which aimed to recruit participants that had the relevant characteristics, knowledge and experience to meet the study objectives (Ritchie and Lewis, 2004).

**Table 10: Study design and methods (n = 18)**

Theoretical foundation	Cognitive development		Child-parent transfer of asthma management responsibility	Locus of control	Health belief model	Behavioural theory	Not stated		
Number of studies*	4		2	2	3	2	8		
Research approach	Quantitative		Qualitative						
			Descriptive	Phenomenology		Grounded theory		Ethnography	
Number of studies**	5		11	2		1		1	
Data collection	Survey		Focus group			Interviews		Focus group and interviews	
Number of studies	2		1			12		3	
Data analysis	Statistical analysis	Phenom-enology	Grounded Theory	Thematic analysis		Content analysis	Framework approach	Not stated	
Number of studies**	4	2	2	3		3	3	3	

\*3 studies adopted more than one theoretical framework to underpin the research \*\* 3 studies used mixed methods

Three studies used the framework approach to analyse data (Meah *et al.*, 2009; Taylor *et al.*, 2009; Williams *et al.*, 2007), two phenomenology (Cashin *et al.*, 2008; Fereday *et al.*, 2009), two grounded theory (Miller *et al.*, 2008; Buford, 2004), three studies used thematic analysis (Hafetz and Miller, 2010; Meng and McConnell, 2002; Miller, 2009) and three studies used content analysis (Pritchard, 2012; Miller *et al.*, 2008; Pradel *et al.*, 2001). Three of the qualitative studies did not state the data analytical methods undertaken (Newbould *et al.*, 2008; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b). The quantitative studies used multivariate regression statistical analysis (Miller and Harris, 2012; Kieckhefer *et al.*, 2009); and Pearson's product-moment correlation coefficient (Chisholm *et al.*, 2012). The mixed-

methods studies employed: validated measure of child cognitive development (Miller *et al.*, 2008); and frequency analyses to analyse the quantitative data but details of the qualitative analysis component were not provided (Newbould *et al.*, 2008).

### **3.5 Summary of the quality appraisal assessment**

The quality appraisal assessment criteria focussed on three key areas: rigour; credibility and relevance within the qualitative research (Long *et al.*, 2002a; Long *et al.*, 2002b; CASP, 1998). Rigour refers to the appropriateness of the research design and methods employed; credibility refers to whether the researcher has remained true to the data, are the findings discussed in relation to the study objectives and whether the researcher has critically examined their own role within the study; relevance refers to the findings in relation to current practice or policy and the usefulness of the findings. These areas are now described.

#### **3.5.1 Rigour, Credibility and Relevance**

Quality of the studies varied and a summary of the quality appraisal assessment for the qualitative and quantitative studies are presented in Appendix 3 and 4, respectively. The study designs and methods of the studies reviewed appeared appropriate to address the aims and objectives of the research. Thirteen studies employed qualitative methods, with the explicit aim of gaining an in-depth insight into child and/or parent perspective of the shared decision-making for managing the child's long-term condition (Pritchard, 2012; Hafetz and Miller, 2010; Meah *et al.*, 2009; Taylor *et al.*, 2009; Fereday *et al.*, 2009; Miller, 2009; Cashin *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Meng and McConnell, 2002; Pradel *et al.*, 2001). Three studies employed quantitative methods: to develop a decision-making involvement scale (Miller and Harris, 2012); to explore communication in children with type 1 diabetes and their mothers (Chisholm *et al.*, 2012); measuring parent-child shared management of chronic illness (Kieckhefer *et al.*, 2009). Two studies used mixed methods; to examine the partnership between children and their parents in the management of medication for asthma and diabetes (Newbould *et al.*, 2008); and to assess the child's verbal ability, as an indication of their cognitive development (Miller *et al.*, 2008).



Data collection methods appeared congruent with the research design for the qualitative studies reviewed with interviewing used to elicit data in 16 of the 18 studies (Chisholm, 2012; Pritchard, 2012; Hafetz and Miller, 2010; Miller, 2009; Taylor *et al.*, 2009; Meah *et al.*, 2009; Fereday *et al.*, 2009; Miller *et al.*, 2008; Newbould *et al.*, 2008; Cashin *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Meng and McConnell, 2002; Pradel *et al.*, 2001). Interviewing is the most common data collection method in qualitative research because it allows an in-depth exploration of an individual's perspective (Sandelowski, 2000). Interview guides were included in the following studies: Hafetz and Miller, 2010 (parent interview template only); Miller, 2009; Fereday *et al.*, 2009; Cashin *et al.*, 2008 (parent interview template only); Miller *et al.*, 2008; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Meng and McConnell, 2002); and appeared appropriate to meet the study aims. Studies developed their guides from the examination of the available research and consideration of their own research objectives (Miller, 2009; Taylor *et al.*, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007; Meng and McConnell, 2002). With one exception (Taylor *et al.*, 2009), interviews with children and parents were undertaken separately. Taylor *et al.* (2009) indicated that for ethical and practical reasons the children were interviewed in the presence of their parent, but acknowledged joint interviews may have affected the child's response. Despite the legal and ethical guidelines suggesting parents should be present when interviewing children (National Research Ethics Service, 2011; British Psychological Society, 2010) conducting separate in-depth interviews may facilitate a more open response from the children.

Incongruence between the theoretical perspectives and methods adopted was evident. For example; Newbould *et al.* (2008) employed the use of structured and open-ended questions during individual interviews to elicit quantitative data, rather than methods usually associated with the chosen approach. Further examples are evident: within one of the studies, focus groups were employed as a method of data collection (Meng and McConnell, 2002) and three studies used focus groups in conjunction with in-depth interviews (Hafetz and Miller, 2010; Fereday *et al.*, 2009; Miller, 2009). Although focus groups may elicit 'rich data' from the participants, they may not be the most appropriate method of gathering data from children (MacDonald and Greggans, 2008). Some children may not feel comfortable

sharing information with other children and issues of reinforcing confidentiality, within the group, may be an issue. Young children may not be able to understand the open-ended questions especially in relation to an abstract concept like 'decision-making'. One study focussed on age related theory and child demonstration of autonomous illness related decisions (Pradel *et al.*, 2001). Child structured drawing activities and semi-structured interviews were employed to elicit data. Although qualitative methodology was employed and the design of the study appropriate, this study has identified weaknesses: the interview questions did not appear to meet the aims of the study because; the interviews focussed on the management of an acute asthma episode rather than the day-to-day management and the decision-making process between child and parent for illness related tasks. Fereday *et al.* (2009) undertook focus groups and individual interviews with children eliciting data through multiple qualitative data collection methods. Congruence between the chosen theoretical perspective and methods used, are typical of phenomenology, enabling a detailed description of the lived experience of living with a long-term condition is elicited from participants (Fereday *et al.*, 2009). The methods employed by studies reviewed are discussed further in Chapter 4, Section 4.7.

Overall the procedures relating to the analysis of data were sufficiently rigorous. Framework approach (Meah *et al.*, 2009; Taylor *et al.*, 2009; Williams *et al.*, 2007) and thematic analysis (Hafetz and Miller, 2010; Miller, 2009; Meng and McConnell, 2002) were the most common choices of qualitative data analysis (Table 10). The authors of the twelve studies provided a detailed description of the procedures and stages involved in data analysis (Chisholm *et al.*, 2012; Miller and Harris, 2012; Pritchard, 2012; Hafetz and Miller, 2010; Meah *et al.*, 2009; Taylor *et al.*, 2009; Fereday *et al.*, 2009; Miller, 2009; Miller *et al.*, 2008; Cashin *et al.*, 2008; Williams *et al.*, 2007; Pradel *et al.*, 2001). For example, Cashin *et al.* (2008) use three experienced qualitative researchers to analyse the data. The findings are made explicit as: the researcher presents sufficient data to support the findings, explaining how the presented data was selected from the narratives (Cashin *et al.*, 2008); and each participating father was sent an individual Interpretive Summary of their interview to confirm the researcher interpretation of the findings (Cashin *et al.*, 2008; CASP, 1998). Phenomenology (Fereday *et al.*, 2009; Cashin *et al.*, 2008), grounded theory (Miller *et al.*, 2008; Buford, 2004) and

content analysis (Pritchard, 2012; Pradel *et al.*, 2001) was a preferred choice of data analysis for six of the reviewed studies; providing more depth to the findings. For example, Cashin *et al.* (1998) used hermeneutic phenomenology to analyse the data (Van Manen, 1994), allowing for similarities within the data but also an inductive method enables meaning and understanding to be captured through interpretation of the data (Van Manen, 1994). Congruence between the theoretical perspectives and methods adopted was evident (Appendix 3). For example Buford (2004) used theoretical sampling strategies associated with the chosen approach (Caelli *et al.*, 2003) and open-ended interview questions were modified as the data collection and concurrent data analysis progressed, allowing exploration of emerging theoretical issues (Petty *et al.*, 2012; Strauss and Corbin, 1998).

Strategies employed to enhance the credibility of the study findings is acknowledged through an in-depth description of the analysis process including details of the number of researchers coding the data and interpreting the findings. For example 50% of the transcripts were coded by a second independent coder and any discrepancies were resolved through mutual discussion with the first coder (Hafetz and Miller, 2010). Equally important is the demonstration of the transparency of the data coding and interpretations of the findings. For example detailed stages of the data analysis were well presented in several of the studies (Chisholm *et al.*, 2012; Hafetz and Miller, 2010; Meah *et al.*, 2009; Fereday *et al.*, 2009; Cashin *et al.*, 2008; Williams *et al.*, 2007; Alderson *et al.*, 2006b; Pradel *et al.*, 2001), enabling the reader to make judgements about the way the researcher has interpreted the data. An abundance of quotes from the children and parents promote the transparency of the data findings, as illustrated in Miller's study (2009). In addition, an audit trail of interview guides, transcripts, recorded materials, detailed explanation of how data was generated and analysed, decision about coding and negotiation with a second coder were described (Miller, 2009).

In contrast, Meng and McConnell (2002), present six themes emerging from the data without a detailed description of the procedures and stages involved in data analysis, any justification for their interpretation, thus limiting the credibility of the study findings. Buford (2004) employed the use of a second researcher experienced in the use of grounded theory and two paediatric nursing graduate students, with over five years clinical practice, to assist

in coding the findings. Although this suggests increased credibility with a larger team coming to a consensus, the limited experience of two paediatric graduates may have negatively influenced the credibility of the study findings. The findings of Chisholm *et al.* (2012) must be treated with caution due to the small quantitative sample of 26 participants. Acknowledging researcher personal biases is equally important in raising the credibility of study findings (Long and Johnson, 2000). Only in one study did researchers acknowledge how their personal biases may have affected the study findings (Pradel *et al.*, 2001). For example: researcher incompetence, although it was acknowledged attendance at a two-day workshop on qualitative data collection techniques was undertaken prior to commencing the study and skills refined during the pilot study (Pradel *et al.*, 2001).

Relevance relates to: whether the researcher has discussed the findings in relation to transferability to other settings/populations (CASP, 1998; Long *et al.*, 2002a; Long *et al.*, 2002b; Popay *et al.*, 1998); and have the findings been considered in relation to current practice/policy and the existing literature (CASP, 1998). Overall, the relevance of the findings within each study is presented well and links with existing literature. The majority of the studies are undertaken in the UK and USA, although findings within the UK studies may not be transferrable to other countries for example USA and Australia, due to enforced healthcare costs. Deprived families may not be able to afford private healthcare for their child's long-term condition which may affect the availability of self-management support services (Finklestein *et al.*, 2002), consequently impacting on the child-parent shared decision-making process. Therefore, to avoid health care costs, parents may be more reluctant to share management decisions (Goble, 2004).

### **3.6 Findings**

There were similarities and differences across the findings of the studies. A key objective of the review was to identify the facilitators and barriers to child-parent shared decision-making, as a result these two core themes emerged from the synthesis, with nine embedded categories (Table 11).

**Table 11: Child-parent shared decision-making for long-term condition management**

Theme	Categories
<b>Facilitators enabling child-parent shared decision-making</b>	Locus of control for both child and parent (Miller and Harris, 2012; Fereday <i>et al.</i> , 2009; Williams <i>et al.</i> , 2007; Meng and McConnell, 2002)
	Child's developing cognition (Miller and Harris, 2012; Miller, 2009; Meah <i>et al.</i> , 2009; Miller <i>et al.</i> , 2008; Newbould <i>et al.</i> , 2008; Fereday <i>et al.</i> , 2007; Buford, 2004; Pradel <i>et al.</i> , 2001)
	Child and parent's value of transferring care responsibility (Miller and Harris, 2012; Miller, 2009; Fereday <i>et al.</i> , 2009; Miller <i>et al.</i> , 2008)
	Incorporating the management of the child's long-term condition within family life (Kieckhefer <i>et al.</i> , 2009; Alderson <i>et al.</i> , 2006b)
	Effective health care professionals support (Meah <i>et al.</i> , 2009; Fereday <i>et al.</i> , 2009; Kieckhefer <i>et al.</i> , 2009; Williams <i>et al.</i> , 2007; Buford, 2004; Pradel <i>et al.</i> , 2001; Meng and McConnell, 2002)
<b>Barriers hindering child-parent shared decision-making</b>	Severity of illness (Taylor <i>et al.</i> , 2009; Miller, 2009; Newbould <i>et al.</i> , 2008; Williams <i>et al.</i> , 2007)
	Parents retain control of the management of child's condition (Taylor <i>et al.</i> , 2009; Miller, 2009; Newbould <i>et al.</i> , 2008; Williams <i>et al.</i> , 2007; Buford, 2004; Meng and McConnell, 2002)
	Consequences of sharing responsibility of the care management (Miller, 2009; Buford, 2004)
	Discord between child and parents/adults in relation to care responsibilities (Fereday <i>et al.</i> , 2009; Cashin <i>et al.</i> , 2008; Alderson <i>et al.</i> , 2006b; Meng and McConnell, 2002; Pradel, 2001)

### 3.6.1 *Facilitators enabling child-parent shared decision-making*

A range of factors that facilitate child-parent shared decision-making were identified and these were grouped into five interlinked categories:

- Locus of control for both child and parent
- Child's developing cognition
- Child-parent's value of transferring care responsibility
- Incorporating the management of the child's long-term condition within family life
- Effective health care professionals support

#### *Locus of control both child and parent*

Two studies included in the review, identified that children with a strong internal locus of control contribute to decision-making and perceive they are able to influence decisions

about the management of their long-term condition (Miller and Harris, 2012; Williams *et al.*, 2007). Children were found to be positive about being included in the decision-making process which increased their perceived control of their condition and improved adherence to medication (Miller, 2009). In addition, children with a strong internal locus of control were more likely to be autonomous decision-makers due to an increased knowledge about their asthma condition and recognising their treatment decisions would positively affect their asthma management (Meng and McConnell, 2002). Across a range of long-term conditions, children aged between four and sixteen years of age were found to be capable, depending on their motivation and commensurate with their cognitive development, of taking on some of the responsibility for the management of their condition (Fereday *et al.*, 2009). Parents that participated in the same study reported being proactive in supporting their child to become independent (Fereday *et al.*, 2009). Decision-making was highlighted as a factor that contributed to the child having confidence to participate in school and family activities rather than the long-term condition and chronic illness being seen as a barrier (Fereday *et al.*, 2009). Shared decision-making enabled the child to participate in decisions about their care and treatments without having the responsibility of total control (Miller and Harris, 2012; Miller *et al.*, 2008).

### *Child's developing cognition*

As a child's cognitive development increased, greater knowledge of their condition helped facilitate children to appreciate the risks and benefits of their treatment (Miller and Harris, 2012; Miller *et al.*, 2008). The child's developing cognition was linked to parents' attitudes towards transferring care responsibility. Findings suggested that parents relinquishing control over the management decisions to their child were influenced by parental confidence in their child's cognitive ability and reasoning skills (Meah *et al.*, 2009; Miller, 2009; Pradel *et al.*, 2001, Buford, 2004). Parents acknowledge that as the child's level of knowledge and skills at managing their condition increase this corresponds with an increased responsibility within the decision-making process and within family life (Miller, 2009). Parents were less likely to take control of the decision with increasing child cognitive development (Miller *et al.*, 2008).

Parents needed reassurance that the child was aware of illness symptoms and sought or initiated appropriate interventions (Williams *et al.*, 2007). According to Buford's (2004) theoretical model for child-parent transfer of asthma responsibility, 'gaining control' was identified as a transition stage where the parent retains overall management of their child's condition, but begins to involve the child in care decisions. In this transition stage the child is around five to eight years of age. Children are able to identify changes in their body and initiate appropriate management strategies in response to acute illness symptoms (Meah *et al.*, 2009; Miller, 2009; Alderson *et al.*, 2006a; Pradel *et al.*, 2001). In relation to asthma, it has been suggested that children younger than eight years of age can recognise illness symptoms and need for medication, but may not make other decisions, such as trigger avoidance (Buford 2004).

#### *Child-parent's value of transferring care responsibility*

During the 'empowerment stage' of Buford's (2004) theoretical model for child-parent transfer of asthma responsibility, when the child is approximately eleven years of age, the child assumes greater responsibility for the management of their condition and can initiate broader management decisions such as trigger avoidance. Although there is a relationship between chronological age and increased child responsibility for asthma management (Meah *et al.* 2003), children were more likely to be involved within the decision-making process when they were in a supportive environment (Chisholm *et al.*, 2012; Taylor *et al.*, 2009). The child is able to apply a logical thought process to existing problems, for example, respond to illness symptoms. Increased child autonomy and fostering independence by involving the child in healthcare decisions can improve adherence to medication (Williams *et al.*, 2007). Although older children demonstrate increased independent decision-making and reasoning skills, younger children are more likely to rely on parents to make decisions about their care (Williams *et al.*, 2007). The level of child participation within the decision-making process appears dependent on parental support (Williams *et al.*, 2007). Transferring care decisions provided the child with the confidence to make treatment decisions (Miller and Harris, 2012; Miller, 2009; Miller *et al.*, 2008; Pradel *et al.*, 2001) or participate within day-to-day leisure and physical activities (Fereday *et al.*, 2009). Children report they share the

decision with their parent even when they believed it should be their own autonomous decision (Miller *et al.*, 2008).

*Incorporating the management of the child's long-term condition within family life*

Collaboration between the child and parent appears to facilitate incorporating the management of the child's long-term condition within family life (Fereday *et al.*, 2009). Children initially make autonomous decisions about illness symptoms at school or a sleep-over without parents, with the gradual transferring of acquired management skills to the home environment (Newbould *et al.*, 2008; Buford, 2004). Many parents reported the transition as a normal part of growing up or when the parent realised the child's need for control (Newbould *et al.*, 2008; Buford, 2004). Through experience of managing the condition the family are more intuitive to meeting their child's needs, often operating on 'autopilot', which can assist in transferring decisions from parent to child (Miller, 2009; Meah *et al.*, 2009; Williams *et al.*, 2007; Buford 2004). Fathers in particular described the management of their child's long-term condition as a joint child-parent endeavour (Cashin *et al.*, 2008). However, children may neglect to inform their parents of illness episodes when outside the home environment (Hafetz and Miller, 2010; Miller, 2009), this finding represents the child's control to: avoid treatment; to continue leisure activity without restrictions imposed by the parent; to '*be strong*'; and to '*prevent the parent from worrying*' (Miller, 2009; p253). Explanations for this behaviour also include forgetfulness or intentional behaviour to manage their condition in such a way that will not impact on their daily life (Miller, 2009; Meah *et al.*, 2009). Children perceived that shared decision-making is enacted through discussing aspects of the disease management with their parents and negotiating or compromising to solve condition related issues (Miller, 2009). Children and parents acknowledge an increased level of knowledge and skill demonstrated by the child, awareness of the symptoms and realising when support is required fosters the ability to share the management of the child's condition (Miller, 2009). Child-parent collaboration of decisions results positively in incorporating the management of the long-term condition within family life (Fereday *et al.*, 2009; Miller, 2009; Cashin *et al.*, 2008; Buford, 2004).



### *Effective health care professionals support*

Effective external support from health care professionals and children was reported across studies as an important aspect of facilitating the child to become involved in care decisions. Providing the child and parent with relevant information and support to assist with the decision-making and moving from a position of parent to child control for the management of their long-term condition (Meah *et al.*, 2009; Williams *et al.*, 2007; Buford, 2004; Pradel *et al.*, 2001), requires equipping the parent with necessary assertive communication skills to avoid friction with the child during the decision-making process (Meng and McConnell, 2002). Parents express concern regarding their child's asthma management in school (Cashin *et al.*, 2008; Meng and McConnell, 2002). For asthma education to be effective it needs to extend out of the review consultation and into the school setting (Meng and McConnell, 2002). The school nurse plays a pivotal role in educating the child and school staff on providing a safe school environment for the child with a long-term condition, such as asthma (Cashin *et al.*, 2008). Education provides a safe collaborative working environment and consequently effective overt asthma management between the child, parent, school staff and health care professionals, instead of the child covertly carrying their own asthma medication, against school policy (Cashin *et al.*, 2008). Effective advice and support from the health care professionals empower the child and parent to share decisions leading to a gradual progression of the parent-child transfer of management decisions for the long-term condition (Meah *et al.*, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007; Buford, 2004; Meng and McConnell, 2002; Pradel *et al.*, 2001).

### **3.6.2 Barriers hindering child-parent decision-making**

A range of barriers that potentially hinder child-parent shared decision-making were identified and these grouped into four categories:

- Severity of illness
- Parents retain control in the management of child's condition
- Consequences of sharing responsibility of care management
- Discord between child and parents/other adult in relation to care responsibilities

### *Severity of illness*

The severity and occurrence of acute illness symptoms, which may require emergency admission to hospital at times, dominated family life and changed the level at which children were involved in care decisions (Taylor *et al.*, 2009; Miller, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007). In the context of asthma, parents expressed frustration at continually reminding their child to administer the preventative inhaler, particularly in children between the ages of seven and twelve (Miller, 2009; Meng and McConnell, 2002). Despite education from the parent, children do not appear to have the cognitive ability to understand abstract concepts such as preventive treatment and expressed their frustration with the parent continually providing negative feedback; resulting in reduced child internal locus of control and reduced motivation in managing their long-term condition. According to Buford's (2004) theoretical model for child-parent transfer of asthma responsibility, taking responsibility for the administration of the preventative inhaler is the final asthma management task to be achieved by the child. One study highlighted only one child from 32 children with asthma, aged between seven years and twelve years, was able to identify the difference between a preventative and a broncho-dilator inhaler (Pradel *et al.* 2001), suggesting increased knowledge through education is required. These findings suggest limitations of the decisions that children, especially younger children, are able effectively to participate within.

A range of factors influence the child's desire to live a 'normal' life and 'get on with their lives' (Alderson *et al.*, 2006b). For example, ignoring or mismanaging their long-term condition so that they are perceived as the same as other children living without a long-term condition (Miller, 2009). Children report situations when they have been excluded from activities such as not being permitted to go on a school outing, missing play time or not being allowed at sleep-overs because of having a long-term condition (Alderson *et al.*, 2006b). Decision-making may reduce the restrictions imposed by others on the child's leisure activities. Child and parent lack of knowledge of the long-term condition and management tasks involved may have a negative effect on the child, resulting in preventable exacerbation of the condition (Buford, 2004).

### *Parents retain control in the management of child's condition*

When the severity of the illness increases the level of child participation within the decision-making process is often shifted back to being parent dominated (Taylor *et al.*, 2009; Miller, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007). Although children identify concerns about asthma symptoms, they often ignore early warning signs in order to continue with their daily activities resulting in an acute illness episode (Miller, 2009; Meng and McConnell, 2002). Parental sense of responsibility, duty and purpose can impact on level of child-parent decision-making (Hafetz and Miller, 2010; Taylor *et al.*, 2009). For some parents they never fully relinquish responsibility of the management of their child's long-term condition (Miller, 2009; Taylor *et al.*, 2009). Fear, uncertainty and guilt have been identified as contributing to the parent's reluctance to bequeath control (Buford, 2004). The parent's obstruction in transferring the asthma management decisions to their child may result in tension and friction. None of the studies identified within this literature review have unpicked the different processes and scenarios the child and parent experience during potential contentious decisions on asthma management.

### *Consequences of sharing responsibility of care management*

The management of a long-term condition can involve complex daily routines that need to be maintained. These management tasks may be difficult for parents, who require the necessary skills and knowledge before the transition of the management is able to be transferred to their child (Buford, 2004). Family pressures may lead to parents dominating care decisions, which can limit the inclusion of the child within the decision-making process (Miller, 2009). Factors such as single parent families, low income families and carer demands have been suggested as reasons that negatively influence child-parent shared decision-making (Meng and McConnell, 2002). Indeed living with a child with a long-term condition results in additional challenges above usual parenting responsibilities (Smith *et al.*, 2013; Kratz *et al.*, 2009; Ray, 2002). Parents are often frustrated with the child's lack of responsibility in managing their long-term condition, particularly the need for prompting for the child to take their preventative inhaler (Miller, 2009; Buford, 2004; Meng and McConnell, 2002).

*Discord between child and parents/other adult in relation to care responsibilities*

Children report that school protocols restrict their ability to manage their condition, for example lack of access to medication (Cashin *et al.*, 2008). Poor management of asthma at school impacts on the internal locus of control for the child and consequently their decision-making. Indeed both children and parents report concerns about the delay and administration of asthma medication in the school environment. This includes the lack of accessibility to medication, teachers' lack of knowledge and skills in relation to managing acute asthma symptoms and the limited access to the school nurse (Cashin *et al.*, 2008; Meng and McConnell, 2002). Children often carry their own medication, against school policy (Cashin *et al.* 2008; Meng and McConnell, 2002). Children recognise that exercise is a potential trigger and may induce an asthma attack but that building the level of exercise gradually can reduce exercise-induced risk but report they are restricted from taking part in exercise by teachers (Meng and McConnell, 2002). Indeed, participating in physical exercise was identified as a source of friction between child and parent (Fereday *et al.*, 2009; Meng and McConnell, 2002; Pradel *et al.*, 2001). Across long-term conditions, children and parents do not always actively share decisions about the child's participation in leisure activities (Hafetz and Miller, 2010; Miller, 2009; Fereday *et al.*, 2009; Buford, 2004; Meng and McConnell, 2002). Parents may limit the child's participation in leisure activities to prevent an exacerbation in the child's condition (Meng and McConnell, 2002). However, tension could be reduced if undertaking exercise was supported and built into care plans through negotiation with health care professionals (Fereday *et al.*, 2009).

In terms of overall methodological quality the reviewed papers were assessed as being of sufficient methodological quality following evaluation based on appropriate CASP tools (Appendix 3), to generate reliable results or make firm conclusions on effectiveness. However, the majority of the studies did not consider the researcher's influences on findings; eight of the studies lacked a theoretical foundation; and five studies either did not meet or only partially met the criteria for ensuring rigor of the data analysis. Although, the majority of the reviewed studies were undertaken in the UK or USA, asthma is a global child health condition. Therefore the review mainly reflects health care and service delivery in developed countries.

### 3.7 Review limitations

The review has several limitations. First, with a review protocol searching is not an exact science, although I endeavoured to identify articles there is also a chance one or two may have been missed. Searching databases because of the way articles are indexed may not include all relevant articles (Hudon *et al.*, 2011). Undertaking a systematic review, where a wider range of databases are searched may have identified additional articles. Second, due to lack of evidence on asthma shared decision-making findings are for child-parent decision-making of long-term conditions, which may be slightly different. However, the synthesis of the studies indicated consensus across the different studies suggesting similar experiences irrespective of condition. Data pertaining to shared decision-making for asthma management was not able to be extracted from the other long-term conditions. It cannot be assumed the same child-parent management decisions exist for similar long-term conditions. The third limitation refers to the geographical location of the studies; six were conducted within the UK and the participants' accounts may not be representative of the ethnic minority groups, ethnic diverse sample was recruited in one study (Taylor *et al.*, 2010) and/or deprived areas that exist within the UK. Indeed studies outside of the UK may also differ in asthma management.

### 3.8 Discussion

This review aimed to summarise and critically evaluate the literature pertaining to child and/or parent perspective on shared decision-making in the management of a long-term condition. The findings presented have addressed two of the reviews specific objectives; to identify and summarise research that has explored child-parent shared decision-making in the context of children living with a long-term condition; and explore how research has been undertaken in relation to child-parent's shared decision-making. The remaining objective, exploring the facilitators and barriers that enable or hinder child-parent shared decision-making in the context of children living with a long-term condition will be discussed by making links to the theories or frameworks that may be useful to guide practice in relation to supporting child-parent shared decision-making presented in Chapter 2.

### **3.8.1 Theoretical perspectives**

The progression of the child's decision-making and reasoning skills appears congruent with Piaget's concrete operational stage of cognitive development (Piaget, 1969). However, it has been argued for the past 30 years, children can be taught and achieve management task for their long-term condition with adequate support from a more knowledgeable adult (Vygotsky, 1978; Donaldson, 1978). The reviewed studies identified key facilitators enabling child-parent shared decision-making and include: child's perceived internal locus of control encouraged greater participation of the child within the decision-making in the management of the long-term condition (Miller and Harris, 2012; Fereday, 2009; Williams *et al.*, 2007; Meng and McConnell, 2002). The child's cognitive development influenced the degree of management decisions the parent was willing to share (Meah *et al.*, 2009; Miller, 2009; Newbould *et al.*, 2008; Buford, 2004; Pradel *et al.*, 2001). The majority of the reviewed studies employ a model or theoretical underpinning to their research findings which may assist in guiding practice in relation to support child-parent shared decision-making. These include: child's cognitive development (Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Miller *et al.*, 2008; Pradel *et al.*, 2001); parent-child transfer of asthma management responsibility (Meah *et al.*, 2009; Buford, 2004); child/parent perceived locus of control (Miller and Harris, 2012; Meng and McConnell, 2002); behavioural theory (Meah *et al.*, 2009; Kieckhefer *et al.*, 2009; Williams *et al.*, 2007; Meng and McConnell, 2002; Pradel *et al.*, 2001).

### **3.8.2 Approaches to researching the topic of child-parent shared decision-making**

Many facets of child-parent shared decision-making in the context of living with a long-term condition were explored which included: the process of transfer of management responsibility from parent to child as a complex process occurring over years and consists of five stages (Buford, 2004); the child and parent perception of the benefits of management facilitate transfer of responsibilities; the available physical, psychological and sociological resources enable the transfer (Williams *et al.*, 2007); a child with a long-term condition participating within medical research decision, review findings identified that child-parent collaborative decision-making was associated with the child's increasing cognitive development (Miller *et al.*, 2008); a child required specific skills to enable participation within medical research (Alderson *et al.*, 2006b); child-parent collaborative decision-making

is vital to a child's self-management of their long-term condition (Miller, 2009); and children with a long-term condition just want to live a normal life (Alderson *et al.*, 2006a). A specific division of decisions relating to management tasks (Miller and Harris, 2012; Hafetz and Miller, 2010; Fereday *et al.*, 2009; Newbould *et al.*, 2008), context specific for example school issues (Meng and McConnell, 2002); decisions associated with health care advice and support of which children want to be involved (Pritchard, 2012; Taylor *et al.*, 2009) and parents request assistance from health care professionals in managing the transition from parent to child autonomy (Meah *et al.*, 2009; Buford, 2004).

The structured review identified how previous researchers, within this topic area, have designed their studies. A range of methodologies with differing epistemological and ontological assumptions have been employed. The majority of the reviewed studies employed qualitative methodology; three review studies used a quantitative design (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009); two used a mixed methods design combining qualitative and quantitative methods (Newbould *et al.*, 2008; Miller *et al.*, 2008). Each of the study designs were congruent with the study aims, for example; one of the objectives of Newbould *et al.*'s. (2007) study was to document how responsibilities for the management of medication was shared, consequently requiring frequency analyses statistical testing of the data. A second objective was to identify the factors that lead to the transfer of responsibilities (Newbould *et al.*, 2007), conducive with qualitative enquiry. The majority of the studies employed the use of individual in-depth interviews, apart from Taylor *et al.* (2007) who provided explanations as to why they conducted child-parent joint interviews; although they do acknowledge the child's perspective may have been obscured due to their parent's presence. Overall, the studies within the structured review present quotes from the parent (Cashin *et al.*, 2008); the child's perspective through the parent's voice (Taylor *et al.*, 2009; Williams *et al.*, 2007; Buford, 2004;); and quotes from the child (Hafetz and Miller, 2010; Taylor *et al.*, 2010; Meah *et al.*, 2009; Miller, 2009; Miller *et al.*, 2008; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Pradel *et al.*, 2001). However, an illustration of parent quotes dominating the findings is still evident within Buford's study (2004). 18 parent quotes are presented; one quote from the child's perspective via the parent's voice; with only one quote from the child. Although the child's

voice is heard the parental quotes dominate the findings (Newbould *et al.*, 2008; Williams *et al.*, 2007; Buford, 2004). Similarly, the quotes presented in the study findings of Taylor *et al.* (2009) are from children thirteen years and above, despite the age range of the 21 child participants being aged seven to sixteen years. Problem solving designs may be widely used in observational studies of children (Chisholm *et al.*, 2012) but this method is not congruent with the epistemological and ontological perspectives of the researcher for the study; discussed further in Chapter 4, Section 4.3.

### **3.9 Gaps in the literature**

The available research mainly focuses on the transfer of the management for the long-term condition and addresses the process as two discrete stages; the child or the parent managing the condition. The research does not address the intermediary stage where decisions are shared between the child and parent; specifically focusing on any areas of friction or contentious decisions and how the child and parent work through these scenarios. Although child participants are included within some of the review studies, their voices are marginalised with their perspective often heard through a parent or parent quotes dominated the findings. Children as active agents in decisions that involve them still evades some of the reviewed studies (Cashin *et al.*, 2008; Buford, 2004; Williams *et al.*, 2007). Researchers are still marginalising the voice of the child despite policy directives advocating the child is involved in their care management decisions for a long-term condition (DfES/DH, 2004a; 2004b; Gabe *et al.*, 2004). The perspectives of young children on management decisions of a long-term condition have not been adequately obtained.

There is also a gap in the literature addressing ethnic minority participants, families from areas of deprivation and fathers are also under-represented within this topic area. The shared decision-making literature is also largely concerned with decision-making processes between the health care professional and adult patient (Coulter and Collins, 2011; Gabe *et al.*, 2004; Charles *et al.*, 1997). Literature relating to decision-making within child-parent-professional health setting has primarily focussed on parent-professional dyads, with the assumption that parents are responsible for the child's care. In addition, the shared decision-making evidence has a bias towards treatment decisions with the majority of studies



undertaken in acute care consultations, excluding how children and parents make management decisions within the home environment (Hafetz and Miller, 2010; Taylor *et al.*, 2009; Miller, 2009; Newbould *et al.*, 2008); despite the majority of the management decisions of childhood long-term conditions occurring within the home environment (Kieckhefer *et al.*, 2009; Ray, 2002). There is a paucity of research on child-parent decision-making within the family environment and how responsibilities for the management tasks of the long-term condition are negotiated, especially from a young child's perspective. The theoretical perspective and evidence base, highlighted in Chapters 2 and 3 respectively, offer some explanations about the processes involved in transferring asthma management from the parent to the child but have not considered a possible intermediary stage where children and parents share decisions about asthma management. Therefore, this study will contribute to new knowledge through focusing on the stage of decision-making for asthma management where both the child and parent actively participate within the decision and identify the process of how decisions are worked through and resolved if contention does arise. An in-depth understanding of the child-parent decision-making process has the potential to assist health care professionals when working with the family to identify strategies to support families during the transitional period for asthma management from parent to child, predominantly when friction or contention over the control of the decision may occur.

Decision-making appears to be interchangeable with terms such as 'team decision-making' (Miller, 2009; Newbould *et al.*, 2008), 'patient-professional interactions' (Hafetz and Miller, 2010) and 'partnership working' (Newbould *et al.*, 2008; Miller, 2009). Miller (2009) also described the process of decision-making as a 'dance', where each takes a turn in leading the decision-making process. The thesis will use Miller's (2009:p 249) definition of child-parent decision-making which refers to decision-making as '*the way in which children and parents engage each other in decision-making and problem solving about chronic illness management focusing on both child and parent behaviours.*' The focus for this study will be child-parent decision-making for the management of asthma, as asthma is the most common long-term condition in children (Asthma UK, 2010a) and developing good decision-making skills at a young age could optimise long-term health outcomes. The design and methods of the study undertaken are discussed in the following chapter.

## **4. Introduction**

This chapter presents the research design and methods relating to a study that explored child-parent shared decision-making for the management of childhood asthma, undertaken as part of this thesis. Chapters 1-3 have presented the foundations of existing knowledge and theoretical understanding in relation to managing childhood long-term conditions, highlighting that the transfer of care decisions from parent to child is a gradual process occurring over a period of time. What remains unclear is how shared management decisions occur during this transition. In the context of asthma, for the majority of children, the mainstay of treatment involves taking daily prophylactic inhalers and making decisions about when to take inhaled bronchodilator agents to treat acute breathing difficulties, which can continue into adult life. Successful management strategies implemented by the child and parent can potentially minimise the disruption of asthma on a child's daily life. The study design and methods discussed reflect a desire to ensure both the child and parents views were represented.

### **4.1 Aims and objectives**

The study aimed to explore and describe child-parent decision-making for the management of childhood asthma. The specific objectives were to:

1. Examine how children and parents make joint decisions about asthma management;
2. Understand the process of parent to child transition to enable the child's independent decision-making for their asthma management;
3. Identify the barriers and facilitators that influence child-parent shared decision-making processes in relation to asthma management;

4. Add to the theory of child-parent decision-making, through the development of a conceptual framework that could guide health care professionals when supporting child-parent decision-making, in relation to asthma management.

## **4.2 Rationale for adopting a qualitative approach**

Qualitative research aims to make sense of complex situations, gain new insights and construct themes in order to explain phenomena (Petty *et al.*, 2012; Ritchie and Lewis, 2004; Morse and Richards, 2002). A qualitative research approach was appropriate to foster a deep understanding of the processes relating to child-parent shared decision-making in the context of childhood asthma. Qualitative methodologies recognise that multiple realities exist, which are co-constructed between an individual's differing social perspectives (Holloway, 2005). In the context of this study realities are dependent on both the child and parent subjective interpretations of how they share the decision-making processes; with each participant bringing their own experience and perspective to address the specific objectives of the study. This approach enabled the researcher to acknowledge that the participants were active contributors within the research and not subjects to be studied (Sandelowski, 2000).

A qualitative descriptive interview based design was adopted, underpinned by the principle characteristics of qualitative research methods: obtaining and analysing rich data (Polit and Beck, 2008; Sandelowski, 2000); extensive interaction with participants (Speziale and Carpenter, 2005); a flexible plan of inquiry that is responsive to 'real' world contexts (Paterson and Morin, 2012); 'naturalistic' in study methods (Holloway, 2005: p6; Sandelowski, 2000). Adopting a flexible design enabled data collection and analysis to be an iterative process by responding to participants responses to questions and simultaneously adapting the analytical process as new insight emerged as the study progressed (Patterson and Morin, 2012). This flexibility enabled the revision and development of questions within the interview guide as an iterative process, reflecting on data collection and analytical strategies as an ongoing process and to ensure the study objectives were being addressed. The study was undertaken within the natural environment of the children and their parents,

in this case their home, minimising distress (Greig and Taylor, 2005), respecting their attitudes, feelings and beliefs (Sandelowski, 2000), enabling a naturalistic line of inquiry (Lincoln and Guba, 1985).

Quantitative methodologies have been widely adopted in studies of children seven to twelve years of age to investigate the management of long-term conditions (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009; Newbould *et al.*, 2008; Miller *et al.*, 2008). However, these studies focussed on measuring the perceived level of responsibility for asthma management tasks, using questionnaires to collect data, which offer limited understanding of child-parent decision-making (Miller and Harris, 2012; Chisholm *et al.*, 2012; Kieckhefer *et al.*, 2009; Newbould *et al.*, 2008). Quantitative researchers operate within a positivist paradigm, where there is a search for one reality often based on objective measurement (Holloway, 2005), unlike qualitative research which embraces multiple realities and the different subjective experiences of participants (Speziale and Carpenter, 2005; Boyd, 2001). Data within qualitative research is typically depicted from who, what and where, open-ended questions, in relation to their experiences (Sandelowski, 2000). Within this study, the child and parent were asked similar questions on how they made decisions for the management of the child's asthma, developing a collaborative and participatory approach to data collection, therefore an interpretive rather than a positivist approach was appropriate.

Qualitative research encompasses a range of methodologies with differing ontological and epistemological assumptions (Petty *et al.*, 2012). The range and diversity of approaches can be challenging to the novice researcher when designing a qualitative study (Smith *et al.*, 2011). Study designs identified within the structured review (Chapter 3) relating to child-parent decision-making included; grounded theory (Miller *et al.*, 2008; Buford, 2004), ethnography (Pritchard, 2012) and phenomenology (Fereday *et al.*, 2009; Cashin *et al.*, 2008). These approaches are well established, rooted in the philosophies of social science disciplines of sociology, anthropology and psychology respectively, each having differing epistemological underpinnings and therefore different application in the research setting (Holloway, 2005). Considering the application of the frequently adopted approaches; grounded theory, ethnography and phenomenology to the topic being investigated fostered

an informed choice about which study design best achieved the study objectives (Fraser *et al.*, 2004).

As a research approach, grounded theory aims to develop theory in order to explain the social process, actions or interaction between individuals or groups, with data typically generated through interviews, observation and focus groups (Petty *et al.*, 2012; Holloway, 2005; Duffy *et al.*, 2004). Central to grounded theory is theoretical sampling, where recruiting procedures are refined to purposefully select participants with the experiences that will enable focussed exploration of topics relevant to develop the emerging theory (Petty *et al.*, 2012). Grounded theory underpinned Buford's study (2004), which was described in depth in Chapter 3, where children and parents were interviewed to explore the transfer of responsibility for asthma management from parents to their child. Whilst this approach appeared appropriate to inform health care professionals of the stages involved in transferring asthma management from the parent to the child, the focus was to develop theory and did not describe in depth participants' experiences.

A grounded theory approach could have been adopted within this present study by building on and recognising the child's voice in sharing decisions between the child and the parent, which unlike Buford focussed on reporting parents' perspectives (Buford 2004). However, this study sought to describe child-parent decision-making processes for the management of childhood asthma, rather than develop theory. Although there are similarities with grounded theory in relation to the way data was collected and that data collection and analysis occurred concurrently, there were also differences including participant descriptions were explored by drawing on existing theories and building on the underpinning conceptual framework, presented in Chapters 2 and 3. A key reason for not adopting a grounded theory approach was criticisms of 'selective coding' where the researcher filters and codes data which are relevant to the emerging concepts rather than embracing and valuing participants' accounts in their entirety (Petty *et al.*, 2012:p378). In addition, although this selection of accounts is essential for the development of emergent theory, can be abstract in nature and removed from participants' accounts (Holloway, 2005). One of the underpinning principles of this study was to accurately represent child and parent perspectives in a way that was meaningful and demonstrates transparency of data analysis.

Ethnography, explores individuals within their own community, allowing for a deep understanding of how culture is constructed and negotiated between the community group members (Holloway, 2005; Ritchie and Lewis, 2004; Bear-Lehman, 2004). The key method of data collection includes participant observation and interviewing to obtain the emic, participant's perspective, rather than the etic, researcher's perspective (Harris, 1976). The flexible nature of the interview enables more focussed questions, drawing on observational data within the interview guide (Holloway, 2005). Adopting an ethnographic approach may have been appropriate for this study, as the child and parent are able to be interviewed and observed within their 'natural setting' of the home environment. However, to undertake a rigorous ethnographic study would require being situated for long periods in the family home environment, school or asthma clinic which was considered unrealistic, intrusive and too disruptive for the family.

Unlike ethnography which explores perspectives within a community or group, phenomenological research aims to explore the 'lived experience' of phenomenon to understand the meaning and significance to the individual (Petty *et al.*, 2012; Flood, 2010). Within this approach data collection is usually undertaken through individual interviews which are typically unstructured without predetermined questions (Petty *et al.*, 2012). The purpose of the interview technique is to encourage participants to direct which topics are important to discuss, resulting in data elicitation being participant centred (Holloway, 2005). Phenomenological research aims to explore the subjective meanings within the participants' conversation (Ritchie and Lewis, 2004), an approach used within a study that explored the needs and concerns of fathers living with a child with asthma (Cashin *et al.*, 2008; van Manen, 1998). Whilst unstructured interviews would have elicited the child and parent perspectives this study sought to compare and contrast child and parent perceptions and experiences across family units. Although understanding the individual perspective was significant, this needed to be framed in the context of *how* and *when* children and parents made decisions when managing the child's condition. The child and parent perceptions of who had overall responsibility for decisions and the factors influencing asthma management required a semi-structured interview process to facilitate comparative data.

Approaches to qualitative research not underpinned by a specific philosophical framework such as grounded theory, phenomenology and ethnography, are increasingly being adopted within health and social science disciplines (Caelli *et al.*, 2003; Sandelowski, 2000).

Moreover the critical review of the traditional theoretical qualitative designs highlighted that no one traditional approach would satisfy the aims and objectives of this particular study reinforcing the decision to adopt a more qualitative 'descriptive' design. The use of a generic qualitative research design has evolved as the application and usefulness of qualitative inquiry across different settings, particularly within health, has increased (Caelli *et al.*, 2003; Sandelowski, 2000). Although the terms 'descriptive', 'generic' or 'atheoretical' appear to be used interchangeable, they refer to approaches to undertaking qualitative research without being constrained by a set of intellectual ideas inferred by particular traditions (Holloway and Todres, 2003; Sandelowski, 2000). One reason for linking qualitative research, even loosely, to a theoretical approach however is the criticism that the absence of a theoretical framework results in methodological incongruity and may threaten the credibility of study findings (Reeves *et al.*, 2008; Rolfe 2004; Morse and Richards, 2002). Yet the rigorous application of theoretical frameworks can lead to misinterpretation of participants' accounts (Clancy, 2013; Ritchie and Lewis 2003; Sandelowski 2000). For this study, the term 'qualitative descriptive approach' will be used and refers to qualitative research undertaken in the absence of a specific philosophical framework. Rather than inappropriately claiming to use a traditional approach, it was essential to be clear from the outset that a qualitative descriptive study approach was being used (Sandelowski, 2000).

The advantage of a descriptive approach is that data analysis is more likely to remain true to participants' accounts and ensure the researchers own interpretations are transparent (Clancy, 2013; Sandelowski, 2000). Methods employed are appropriate to answer the question, rather than fitting questions to a particular theoretical framework. Qualitative research is subjective, inductive, based on naturalistic inquiry and many methodologies aim to seek an understanding and thus accurate representation of participants' viewpoint (Greig and Taylor, 2005). This study design embodies the interrelated concepts of interpretation and reflexivity balanced with pragmatism and transparency in order to ensure findings are applicable and useful to health care professionals working with children and parents to

manage the child's asthma. Reflecting on and acknowledging personal values and beliefs that may influence or bias the study were central to choosing a descriptive qualitative approach (Lewis and Ritchie, 2003; Morse and Richards, 2002). During the embryonic stage of the research it was important to ensure my own epistemological and ontological values would be accounted for and any biases acknowledged. As highlighted the multiple realities related to the subjective experiences of both the child and parents perspectives and the co-construction of the knowledge was also influenced by my experiences both as a school nurse and a mother of four children (discussed further within the reflexivity account in Chapter 6, Section 6.10). It was important to value and accurately represent participants' accounts, recognising deeper insights and distinguishing between researcher interpretations and participant's descriptions of decision-making. A qualitative descriptive approach enabled a detailed exploration of how children and parents gave meaning to decision-making in the context of where there has been little research (Kieckhefer *et al.*, 2009; Richards and Morse, 2007; Burkhart *et al.*, 2007; Wade *et al.*, 1999).

### **4.3 Children as research participants**

Children are active participants within the construction of knowledge regarding issues that affect them (Skanfors, 2009; Greig and Taylor, 2005; Mayall, 2002) and are able to provide reliable responses if they understand what is being asked of them (Fraser *et al.*, 2004). The new sociology of childhood has emerged over the past two decades. Following on from the First World War, where children became part of the workforce, the whole concept of childhood was reappraised and the 1970's saw a surge of child development and family research, as children were seen as the '*future of the nation*' (Christensen and James, 2008; Fraser *et al.*, 2004; p30). Resulting in the emergence of child research dominated by child development psychologists (Lutz *et al.*, 2009), in particular Piaget, whose work was particularly influential within developmental psychology (Fraser *et al.*, 2004). As described in Chapter 2, Piaget acknowledged the age-related stages of cognitive development in children but Vygotsky and Donaldson argued for the historical, cultural and social context influencing the child's perspective. Children are best placed to provide their perspective of participation within the decision-making (Alderson *et al.*, 2006a), for their asthma management.



However, a child as a research participant can be vulnerable in terms of ethics (Alderson *et al.*, 2006b), consent (MacDonald and Greggans, 2008; Alderson *et al.*, 2006b), power relations (MacDonald and Greggans, 2008) and methodology (Fraser *et al.*, 2004). A child with asthma may already feel vulnerable as their asthma may single them out as being different (Greig and Taylor, 2005). A child may also feel obliged to participate which may be compounded in the context of having a long-term condition, for example asthma, due to their continuous contact with health care professionals. Undertaking research with children requires an understanding of the nature of childhood, guided by an understanding of child development theories. This enables an understanding of how children's cognition develops, the development of their thought processes and how a child's knowledge and behaviour is influenced by the social and cultural contexts (Lewis and Lindsay, 2002). Children also need to be able to demonstrate appropriate receptive and expressive language to participate within the research (Lewis and Lindsay, 2002:p46). My school nurse role incorporated working with children from aged four to sixteen years and a continuous reflection on the nature of childhood and child development theories. The underlying principles of the theories of childhood (Chapter 2), were continuously utilised within my school nurse role when liaising with the children and their families both within the school and the home environment. Skills gained for example: liaising with a child can take time and patience gaining trust and establishing a rapport is central to forming effective relationships with the child and family; using age related language and experience in interacting with children sensitively were applied to undertaking research with children particularly when seeking informed consent and undertaking interviews (Greig and Taylor, 2005).

Adopting a generic design was more likely to accommodate the differences between child and parent participants, which may have been hindered by adhering to a theoretical position that had favoured either the child or adult. Careful consideration of both, the epistemological and methodological issues are required, for good research to be undertaken with children. It is important the researcher's behaviour, values and roles are considered and expressed throughout the research study. Undertaking research with child participants presents a myriad of challenges including: identification of barriers and boundaries; negotiation; planning and design; access; creating the work environment; reflection

(MacDonald and Greggans, 2008; Greig and Taylor, 2005). Therefore, it is not sufficient to adapt adult-based interview methods, in the hope to elicit a true reflection of the child's perspective. Traditionally, the Piagetian age-related stages of a child's cognitive development and the 'concrete' thinking of children under the age of seven years has influenced researchers reluctance to involve young children as research participants (Morrows and Richards, 1996).

#### **4.4 Setting**

The study was undertaken in East Lancashire where children have their asthma managed by the GP, asthma nurse or paediatrician, dependent on asthma severity. East Lancashire has a population of 370,000 (Office for National Statistics, ONS, 2008) and approximately 30% of the region has been identified as a deprived area (Index of Multiple Deprivation, 2007). This is significant because there is a strong relationship between the index of multiple deprivations and children and young people's health indicators (North West Public Health Observatory, 2009). East Lancashire also has an ethnically diverse population. Black and ethnic minority groups are estimated to be 12%. The predominant race is Pakistani (South East Public Health Authority, 2010). Pakistani groups are the highest ethnic group reporting their health 'is not good' (Public Health England, 2013) therefore participants from this minority ethnic group were important. East Lancashire has been identified as having a high incidence of respiratory disease (ONS, 2008) and was selected for this study due to the higher risk of emergency admission for childhood asthma exacerbations (Asthma UK, 2012; 2007). The East Lancashire Hospital NHS Trust incorporates the Local Authority Districts of Blackburn with Darwen; Hyndburn Ribble Valley; Burnley, Pendle and Rossendale. The area is served by Royal Blackburn Hospital; Burnley General Hospital; Pendle Community Hospital (East Lancashire Hospital NHS Trust, 2013). Burnley General Hospital specialises in elective treatment and urgent care for adults and children. A comprehensive paediatric service is provided for all children under the age of 16 years. A team of staff with expert knowledge and skills provide inpatient, outpatient and day case children's services for a range of conditions, including asthma.

#### 4.5 Sample selection

Typically qualitative researchers describe strategies for recruiting participants as convenience, purposive, snowballing and theoretical sampling (Fereday *et al.*, 2009; Alderson *et al.*, 2006a; Bowling, 2005; Pradel *et al.*, 2001). The main difference between these strategies relates to whether inclusion or exclusion criteria of the participants are predetermined. For example, theoretical sampling is concerned with recruiting participants that can further develop the emerging concepts into theory (Holloway, 2005). Although initial recruitment may be purposive, theoretical sampling strategy deliberately selects participants that will challenge and test out emerging hypotheses, for example focusing on recruiting children with only a single parent and examining differences in decision-making processes (Coyne and Cowley, 2007). Consequently theoretical sampling is an iterative process with recruitment continuing until a robust theory develops (Morse and Field, 1995) and is often associated with grounded theory methodology (Strauss and Corbin, 1998). This type of sampling strategy was not appropriate for this study because data collection using a semi-structured interview with topic guide had been developed in advance of the study and similar questions were used across participants. Indeed, the review of evidence identified that studies of this topic predominantly employed purposeful sampling, to recruit participants with the knowledge and experience to meet study objectives (Cashin *et al.*, 2008; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Buford, 2004; Pradel *et al.*, 2001).

As a sampling strategy, the snowball technique involves the initial recruitment of a group of participants that meet the study aims who then recruit individuals they know and would be willing to participate in the study. While snowball sampling strategies are useful for identifying hard to reach groups this type of sampling was not necessary because children with asthma were accessible from the asthma clinic. A convenience purposive sampling strategy was chosen as the most appropriate for the study because recruitment aimed to recruit children and their parents with relevant knowledge and experience of asthma in order to meet the study objectives (Alderson *et al.*, 2006a; Ritchie and Lewis, 2004), given that the researcher had access to asthma management clinics where a purposive sample was naturally available (Holloway, 2005).

Inclusion criteria were determined in advance of recruiting participants. Participants were included or excluded from the study based on the criteria below.

*Inclusion criteria:*

- Children between seven and eleven years of age and their carers (parent (s) or caregiver). Children have the cognitive ability to understand asthma and contribute to the asthma management decisions;
- Children diagnosed with moderate or severe asthma (SIGN/BTS, 2013), at least six months prior to the commencement of the study. This time frame is likely to ensure participants had sufficient knowledge and experience of asthma management;
- The parent(s) or caregiver is involved in the management of the child's asthma and therefore contribute to the decision-making process for their child's asthma management;
- Participants are able to speak English language, although it was recognised this may exclude some participants from ethnic minority groups, unfortunately, financial and pragmatic constraints were not conducive to employing an interpreter.

*Exclusion criteria:*

- Children with other long term illnesses (e.g. epilepsy and diabetes), as the experience and management of these illnesses may be different from those with asthma. However, children with allergic rhinitis and eczema were not excluded because these conditions are strongly associated with asthma (Fleming, 2010).

There are no recognised methods of predicting sample sizes within qualitative studies (Higginbottom, 2004; Coyne, 1997). Previous similar studies have reported reaching saturation with less than twenty participants (Meah *et al.*, 2009; Cashin *et al.*, 2008; Buford, 2004). Therefore, it was anticipated that approximately twenty participants would provide sufficient depth of information to meet the study objectives. However, it was acknowledged that the number of participants may have increased or decreased depending on the depth and breadth of the data obtained and when new insights ceased to emerge (Smith and Firth, 2011; Richards and Morse, 2007; Holloway, 2005; Ritchie and Lewis, 2004; Popes *et al.*,

2000). This is consistent with other qualitative studies where the aim is to develop a depth of understanding of the phenomenon of interest and not the application of statistical tests to determine correlations of cause and effect (Fereday, 2009; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b). During the recruitment phase of the study, a range of challenges in recruiting participants emerged for example, although families expressed an interest in participating within the study, follow-up contact to arrange the interviews proved difficult. The constraints of ethical approval, and the timing of the PhD meant it was not possible to adapt the recruitment strategy, which limited the final sample. Approval for recruitment from the Site Specific Research and Development with the participating NHS Trust had already been extended from the 30<sup>th</sup> March 2013 to 31<sup>st</sup> May 2013, with clear indication that a further extension would not be granted. Asthma review appointments within the clinics are typically annually or bi-annually therefore the same children would be attending if the recruitment stage of the study was extended.

#### **4.6 Recruitment procedures**

Burnley General Hospital has a designated asthma clinic, staffed by practitioners with expert knowledge of children with moderate to severe asthma. The asthma clinics take place three mornings per calendar month, with scheduled appointments for an average of 35 children at each clinic. The recruitment of participants for the study was from these asthma clinics. Clinic staff were informed of the study and the study protocol was discussed with the consultant paediatrician and the nurse in charge. Access to the site was facilitated by familiarity, having previously worked with one of the paediatricians and members of the nursing staff as a nurse. Previous links afforded a good rapport and acceptance within the clinic during the recruitment phase, with health care professionals recognising my present role as a researcher, not as a nurse. If asked by participants I would have disclosed that I was a qualified nurse, but this situation did not arise. I did not volunteer this information so as not to coerce the child and parent into participating but introduced myself as a research student.

Potential participants were identified by a member of the direct care team from the children's outpatient clinic, who accessed the child's notes to confirm they met the study inclusion criteria. All children between the ages of seven and eleven years of age, with a diagnosis of asthma (over six months), presenting at the asthma clinic were offered the opportunity to participate in the study and provided with an information pack, which consisted of:

- Child and parent participant information sheets (Appendix 5 and 6);
- Child and parent consent forms (Appendix 7 and 8)
- Demographics form (Appendix 9).

The child and parent participant information sheets were developed in accordance with the guidelines provided by the National Research Ethics Service (2011). Using age appropriate language (Long, 2007), the children's information sheet employed short words, sentences and paragraphs (Fraser *et al.*, 2005). Two copies of each consent form were enclosed within the pack, enabling the participants to keep a copy and return a signed copy if they wished to participate.

If potential participants expressed an interest in the study they were introduced to me, the researcher, located in and available during clinics to support the clinical staff in relation to recruitment procedures and provide immediate additional information if required. Once a family was interested in participating within the study I would request contact details (telephone number or email address), enabling parents to be contacted the following week to ask if they or their child, had any further questions regarding the study and to ascertain if they wished to participate. When contact was initiated and both the child and the parent agreed to be involved I would request that they returned, if they had not already, the signed consent forms using the stamped addressed envelope provided within the pack. A mutually convenient time was then arranged to conduct the interviews within the family home. Participants were offered a choice of interview venues; either within their family home or a quiet room within the asthma clinic. All participants chose to be interviewed at their home,

usually the sitting room or dining room, during the early evening at a pre agreed time. Evening appointments were offered to minimise disruption to the child and parent by taking unnecessary time away from school and work, respectively.

#### **4.7 Data collection methods**

One of the strengths of qualitative research is the range of data collection methods such as observation, focus groups or individual interviews that can be utilised in order to obtain rich and meaningful data (Sandelowski, 2000; Wolcott, 1994). A critical analysis of the methods and their application to this study is presented in order to justify the rationale for adopting interviewing as the data collection method to explore child-parent shared decision-making for asthma management. More specifically generating a deeper understanding of how decisions are made, by whom, when, why and in what context.

##### **4.7.1 Focus Groups**

A focus group or group interview has an emphasis on the interaction between participants, with participants encouraged to discuss and debate each other's responses often generating data that has negotiated but has shared meaning (Freeman, 2006). This active interaction becomes part of the analytical process (Holloway, 2005). Focus groups are particularly useful when the researcher is seeking group consensus and how the group negotiate topics and discuss difference and similarities within their experiences (Petty *et al.*, 2012; Miller, 2009). Within this study focus groups could have been used as a method to collate data from groups of children, groups of parents or a mixed group to discuss their views of decision-making and could have enabled child-parent interactions to be observed (Meng and McConnell, 2002). The limitations of undertaking focus group in the context of child-parent decision-making relate to establish relationships between family members may have hindered participants contributing to the focus group, in particular children. Separate child and parent focus groups could even have been undertaken, but may have been difficult for participants to discuss their individual perspectives, if one member of the group dominated the discussion (Miller, 2009). Researchers have integrated focus groups and individual interview data within studies to explore child-parent perceptions of managing a childhood long-term condition, but assume the data collected is comparable and do not always

explicitly explain the rationale for using two data collection methods (Hafetz and Miller, 2010; Miller, 2009). The practicalities of where to host the child and parent focus groups and the time commitment required to undertake separate focus groups would have resulted in time away from school and work respectively, which was not considered appropriate for this study.

#### **4.7.2 Observation**

Observation as a data collection method aims to understand and interpret cultural behaviour and is particularly useful to capture non-verbal communications, the actual events being recorded, rather than relying on participant recall and is traditionally used within ethnographic and grounded theory studies (Holloway, 2005; Mulhall, 2003). Problem solving designs have been used in observational studies of children (Chisholm *et al.*, 2012), but was considered inappropriate as a method of data collection for this study because although the researcher is able to record actions and behaviours as they occur and in more natural circumstances than interviews or focus groups, participants' perceptions of events are not captured. Data obtained from using observation is usually interpreted by the researcher and does not usually involve knowledge co-constructed with participants (Ritchie and Lewis, 2004). Consequently, observation would not capture the child and parent's perspective of the decision-making process. In addition, for pragmatic reasons a researcher's presence in the home environment to capture the decision-making process as they arise, would not be practical.

#### **4.7.3 Interviews**

Interviewing is a well-established data collection method because the research interview enables meaningful engagement with participants allowing them to share their experiences, thoughts, attitudes and beliefs (Holstein and Gubrium, 2003). Interviews may be structured, unstructured or semi-structured (Robson, 2011) and are typically between thirty and ninety minutes (Petty *et al.*, 2012). The decision to undertake semi-structured interviews was influenced by the study's overarching aim to explore in depth participants' experiences and the factors that influence their decision-making for the asthma management. Unlike a structured interview approach, which has similarities with a survey questionnaire that



adheres to a fixed order, the semi-structured interview has some structure but is flexible (Petty *et al.*, 2012). The structured interview is researcher led and usually facilitates limited responses from participants therefore it is unlikely to provide a detailed exploration of child-parent shared decision-making for the management of asthma (Petty *et al.*, 2012; Clifford, 1997). Unstructured interviews differ from semi-structured interviews in the degree topics for discussion are prepared in advance, which for structured interviews are broad, centred around a few key points or an opening question, with subsequent questions developed from participant cues (Petty *et al.*, 2012; Clifford, 1997). A lack of structure and guidance when interviewing children has the potential to create confusion and hinder the depth of data collected (Holloway and Todres, 2003). Mauthner (1997) considered individual interviews to be more suitable for older children and group discussion for younger children. Middle childhood, aged range seven to eleven years respond well with either interviews or a focus group method of data collection (Fraser *et al.*, 2007). There is a perceived unequal power balance between a child participant and an adult researcher (Mauthner, 1997). However, using child participatory techniques such as a drawing exercise recognises the child as social actors in their own right and facilitates the active participation of the child (Christensen and James, 2008; Mayall, 2002).

It was anticipated that a semi-structured interview undertaken with children about shared decision-making for their condition, would facilitate better sharing of their experiences than an unstructured interview. Semi-structured interviewing was congruent with the study aims to explore individual participant's perspectives (Holstein and Gubrium, 2003). Interviewing is often viewed as the 'gold standard' of data collection within qualitative research because interviews facilitate a meaningful engagement with participants (Lambert and Loiselle 2008; Silverman, 2000). In this study, in-depth interviews enabled children and parents to share their experiences, thoughts, attitudes and beliefs about the decision-making process for the management of asthma, an active process and the resultant data was shaped by the participant and interviewer (Richards and Morse, 2007; Bowling, 2005; Cresswell, 2003; Thomas *et al.*, 2003). The effectiveness of interviewing as a data collection method is based on two assumptions: participants having the skills to express their responses in a way that represents their realities; and the researcher having the skills to facilitate participants to

share their stories and experiences and explore participants' response in an ethical manner (Lambert and Loiselle 2008; Holstein and Gubrium 2003; Patton 2003). I drew on my wealth of experience and skills from a school nursing role and mother of four children, to effectively engage with the children and their families.

Individual face-to face semi-structured interviews were undertaken to explore child-parent decision-making for several reasons. Within the semi-structured interview each participant was encouraged to express their individual views; this was enhanced by undertaking separate child and parent interviews. Separate interviews were important because the parent, in a position of power within the relationship, could potentially dominate when responding to questions and there was a danger the child's voice would not be heard (Mauthner, 1997). Although it was acknowledged that a parent's presence in a child's interview may enrich the child's narrative through assisting the child in memory recall of decisions (Irwin and Johnson, 2005), it was decided the child's 'voice' was essential to the study aims and individual interviews best achieved this. Indeed, individual interviews have been used to elicit data from children with a long-term condition (Taylor *et al.*, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007; Buford, 2004; Pradel *et al.*, 2001). Ambiguities within each interview or different perspectives could be clarified and participants' responses explored. At the same time the semi-structured child and parent interview guides (Appendix 10 and 11), allowed core concepts to be explored within each interview, with the wording of the questions responsive to each participant's role and recognising the cognitive development stage of the child, yet facilitated comparisons across the different sample groups and across different families (Smith and Firth, 2011; Holloway and Todres, 2003). The framework approach to data analysis, described in Section 4.8, allowed between and within case analysis of the data.

Individual interviews enabled a child art-based approach to be used with the aim of fostering a rapport to be established between the child and the researcher (Pridmore and Landsdown, 1997). Prior to commencing each interview, time was allowed for general introductions and confirming participants understood the purpose of the interview. In addition to drawing on personal professional experiences as a school nurse working with children and parents in primary health care settings, school and the family home, a range of probing techniques

were used to enhance the quality of the data elicited. This included: allowing silences and thought time; repeating key points and seeking clarification when there were uncertainties about child or parents' responses; offering encouragement by acknowledging participants experiences; and using probing questions to explore issues further (Taylor *et al.*, 2009; Newbould *et al.*, 2008). Interviews were audio-recorded, with the participant's consent and immediately uploaded onto a password protected computer and deleted from the audio recorder as a way of ensuring confidentiality.

There are disadvantages to interviewing as a data collection method which include: interviews are time consuming and information may not be relevant to the study objectives (Lambert and Loiselle, 2008); the topic may be of a sensitive nature and therefore the researcher may be unable to elicit meaningful information (Thomas *et al.*, 2003). The use of prompts was anticipated but care was taken not to interrupt the thought processes that reflect the child or parent thinking which could have limited their response (Miller, 2009). Art based approaches enable a more child-centred method of eliciting data from children (Carter and Ford, 2013). Thereby, commencing the child interview with a drawing activity of 'what their asthma means to them', introduced fun into the research and promoted engagement of the younger child (Carter and Ford, 2013). The child participatory drawing technique was suitable for children of different ages and ability. Participant observation, focus groups, interviews and structured activities have been identified as appropriate methods of data collection for young children (Danby *et al.*, 2011; Kirk, 2006; Kortessluoma *et al.*, 2003; Punch, 2002; Kennedy *et al.*, 2001). Studies which have adopted such methods obtained 'rich data' highlighting child and parent perception and experience of living with a long-term condition; and a child's knowledge, perceptions and autonomy in managing medication for their asthma (Fereday *et al.*, 2009; Pradel *et al.*, 2001). The researcher was familiar to the child and parent due to the former meeting within clinic and subsequent correspondence. This familiarity facilitated rapport building by actively drawing on information gained in the previous encounter in order to positively reinforce the value placed on participant's contribution to the research.

#### **4.7.4 Key considerations when interviewing children**

There has been an increase in family centred care within health (Coyne *et al.*, 2011; Coyne and Harder, 2011; MacDonald and Greggans, 2008; Alderson, 2006a) and childhood studies, which acknowledge the child as having an important 'voice' in all matters affecting them (Tisdall and Punch, 2012; Percy-Smith and Thomas, 2010). Research with children acknowledge the methodological similarities and differences when working with children and adults (Alderson and Morrow, 2011; Tisdall *et al.*, 2009; Thomson, 2008; Kortessluoma *et al.*, 2003); such as developing innovative child friendly methods and tools to collect data from children (Thomson, 2008), enabling flexibility to facilitate cognitive and linguistic ability of each child (Greig and Taylor, 2005). I was respectful that researching with children is different to researching with parents and utilised published guidance relating to working directly with children (Alderson and Morrow, 2011; Tisdall *et al.*, 2009). Good practice guidelines have facilitated the inclusion of hearing the voice of children within research (Moules, 2009; Kirk, 2006; Alderson, 2006a; DH and DfES, 2004). Indeed, in response to the government policy of including children within health decisions that affect them (DH, 2003), research with children informs ethical issues (Alderson and Morrow, 2011); and a better understanding of the extent of a child's active participation (Tisdall *et al.*, 2009). Additional challenges when interviewing young children included obtaining consent, ensuring privacy but not placing the child in a vulnerable situation and ensuring confidentiality (Danby *et al.*, 2011; Kirk, 2006; Mauthner, 1997; Mayall, 1994). Although it has been argued the concept of 'vulnerability' is not unique to researching with children and that if the child is considered competent to participate and engage with the researcher, using the term vulnerability underestimates the child's agency (MacDonald and Greggans, 2008; Morrow and Richards, 1996). In this study a decision was made to interview the child without parental presence to ensure the child's perspective was heard (Gardner and Randall, 2012; Schiller and Einarsdottir, 2009), although the parent was in an adjoining room and was able to enter the room should child or parent desire. The phrasing of questions reflected the age range of the children who participated. Questions were quality checked for clarity and understanding by a child outside of the study, who seven years of age, read through the child's interview guide to confirm questions were understandable.

To maintain consistency within each family interview, the child was always interviewed first. The rationale was primarily to prevent the child waiting to be interviewed and consequently losing interest in participating within the study (Fraser *et al.*, 2004) and to reduce the possibility of the parent remaining within the room, if the child was interviewed following the parent. The aim of the researcher when undertaking the interview was to ensure quality data was obtained (Danby *et al.*, 2011). Research suggests that the researcher has at least one interaction with the child prior to the interview because this assists in developing a rapport with the child in the interview setting (Fontana and Frey, 2000). Cues noted in the asthma clinic where appropriate were used to initiate conversation when meeting the child for the second time. For example one of the children talked about their dog; on attending the family home to undertake the interviews, the child was pleased I had remembered her dog's name and initiated a dialogue about other pets. This facilitated the development of an effective child-researcher relationship that was harnessed during the interview.

Developing an interactive relationship with the child can also be facilitated through playing with the child prior to an interview (Kortessluoma *et al.*, 2003). For example: helping to feed a pet guinea pig, was particularly effective in establishing rapport with an initially quiet child and 'humanised' my role as a researcher. In addition innovative methods of data collection, such as drawing, have been used to increase effective child-researcher rapport (Carter and Ford, 2013), often used in health research settings with young children under twelve years of age (Kennedy *et al.*, 2001; Pridmore and Bendelow, 1995; Williams *et al.*, 1989). Children perceive drawing to be fun and non-threatening (Carter and Ford, 2013; Coad *et al.*, 2009) and this activity was used in this study as an 'ice-breaker' (Fereday *et al.*, 2009; Backett-Milburn and McKie, 1998; Pridmore and Landsdown, 1997), without detracting the child's attention from the proceeding interview (Kennedy *et al.*, 2001). Children were issued with paper, pencils and coloured pencils and asked to draw a picture about their asthma. Analysing the content of children's art work to find meaning is a highly skilled technique and must have a clear purpose (Backett-Milburn and McKie, 1998). No attempts were made to analyse the children's drawings; the art work was referred to in an opening question, but the drawings did not form part of data collection. All of the children appeared to enjoy this

activity and either drew pictures of their medications or of participating within a leisure activity.

The relationship between the researcher and child commenced when the child provided informed consent to participate within the study. Interviewing children within a qualitative study particularly children under eleven years of age, is dependent upon the skills, experience and knowledge of the researcher to engage meaningfully with the child (Kortessluoma *et al.*, 2003). My extensive experience as a school nurse informed how a child's needs differ from their parent, within the interview. In addition, the child interview style was guided by research undertaken by Kortessluoma *et al.* (2003) who advocated:

- Not making a judgement or responding if a child misinterprets a question, but make a mental note to revisit the question or ask it in a different way;
- Maintaining the child's interest and be mindful not to ask too many or too few questions; resulting in confusion by the child or loss of their attention;
- Using an appropriate tone of voice and age appropriate language;
- Maintaining a calm and relaxed atmosphere within the interview as this could directly affect the progress of the interview and ultimately the quality of data obtained;
- Gaining the child's confidence by actively engaging with the child in relation to their experience and knowledge of the topic;
- Avoiding under prompt/over prompt allowing the child to articulate their perspective on asthma management decisions.

#### **4.7.5 Key considerations when interviewing parents**

Both parents were invited to take part in the study therefore decisions had to be made about interviewing couples together or separately. There is a growing literature advocating both for and against interviewing couples together (Macfadyen *et al.*, 2011; Moules, 2009). The literature highlights that interviewing couples together can result in tensions between partners if different views are expressed (Arksey, 1996), which particularly when the research involves sensitive topics may mean individual interviews, not joint interviews,

would be a more appropriate method of choice (Larossa *et al.*, 1981). An important distinction between joint and individual interviews is that one provides an individual's perception of events whilst with the other a shared view is presented (Seymour *et al.*, 1995). However, joint interviewing has been found to help establish a rapport between the couple and the interviewer (Edgell, 1980) and in some instances enhance data collection, as parents are able to facilitate the other's memory recall (Seymour *et al.*, 1995). One study highlighted that within a joint interview men tended to do more talking, often interrupting or speaking on behalf of their partner (Jordan *et al.*, 1992). Within the context of research about living with child with a long-term condition, the voice for the father remains under represented in and had potential to enhance fathers contribution to research (Swallow *et al.*, 2013).

Interviewing parents together was influenced by a desire to minimise disruption for the family. To overcome any tensions during the interview, techniques such as re-directing the conversation back to the other parent for further exploration and making notes on the interview topic guide when one parent changed the direction of the conversation, as a reminder to return and seek the other parents' perspective were used. However, there was also vigilance to minimise the development of that power dynamics within the interview that could result in creating an alliance with one parent by confirming or rejecting differing views between parents (Duggelby, 2005). This was achieved by having empathy with parents and be respective of both parents opinions. Developing rapport potentially increased the time required to undertake the interview, the benefits enabled rich and detailed data to be collected (Seymour *et al.*, 1995). However, only one joint couple interview was undertaken, therefore parent findings mainly represent mother perceptions.

#### **4.7.6 Pilot interviews and schedules**

Separate child and parent interview topic guides were developed from the theoretical perspectives and the existing literature outlined in Chapters 1, 2 and 3. The interview guides were modified, particularly the child's schedule, following review of the pilot interviews (Appendix 10 and 11). Each interview guide consisted of 23 questions and was ordered using the ladder technique (Price, 2002). The ladder techniques suggest moving from descriptive questions to those of a more emotive nature. As a participant-researcher rapport

develops the researcher encourages the participant to provide a full response to a topic they may find emotive (Price, 2002).

Pilot interviews were undertaken with two families, child from the lower age range of seven years and his mum and a child from the upper age range eleven years and both parents. The pilot interviews were undertaken to reflect on and develop the research interview techniques and the appropriateness of the interview guide in relation to meeting the study aims and objectives (Vivar *et al.*, 2007). The responses from these interviews formed part of the final data set because the child and parents' perspectives were a valuable contribution in understanding how the child and their parent make asthma management decisions (Ritchie and Lewis, 2004). The pilot interviews informed the sequence and wording of the questions of subsequent interviews; clarifying the questions enabled the participants to provide responses without constraints; and analysed whether the questions were understood by participants (Vivar *et al.*, 2007; Ritchie and Lewis, 2004). Within the pilot interview some of the children had difficulty understanding the wording of certain questions. For example, question four, the child was asked to 'think about coping at home with asthma and what is the largest thing to cope with?' Following the pilot interviews, in consultation with my supervisors, the wording for question four was revised to 'how do you decide if you need your parent to help you manage your asthma?' As the interviews progressed, familiarity with the questioning resulted in less reliance on the interview guide encouraging a freer flowing discussion (Ritchie and Lewis, 2004). Following the interviews, demographic, medical and family characteristic information was obtained from the parent, including; child gender, age, date diagnosed with asthma, their relationship to the child, other medical conditions, ethnic origin and employment situation of parent. These demographic details provide context to the study findings and are presented in Chapter 5.

#### **4.7.7 Collecting data within the family home**

The ideal of undertaking a 40-60 minute interview in a quiet, calm environment did not always occur (Petty *et al.*, 2012; MacDonald and Greggans, 2008; Williams *et al.*, 2007). The challenges to undertaking interviews in real world contexts included accommodating frequent interruptions from siblings, partners, telephones, dogs, car alarms and the television, whilst simultaneously maintaining rapport and the confidentiality of the



participants' responses. Interviewing in a quiet, calm environment was beyond my control and reinforced the commitment participants had made to participating in the study and giving time voluntarily whilst often managing busy lives (MacDonald and Greggans, 2008). Flexibility was essential as children were frequently commanding parent's attention. Entering participants' homes to undertake data collection can place a lone researcher at risk due to being in an unknown environment. The University of Salford's 'Lone Working & Workers in Hazardous Areas Code of Practice' (2010) was adhered to, which included leaving contact details with the academic supervisor and notifying her when entering and exiting participants' homes.

#### **4.8 Data analysis**

Analytical strategies within qualitative data analysis are diverse with different purposes and epistemological underpinnings (Morse and Richards, 2002). The transparency of the data findings and coding are presented throughout the data analysis. The epistemological underpinnings of this study was to present a description of the child and parent perspectives of decision-making for asthma management, staying close to the data and presenting the findings in the participants' own words, unlike researchers conducting ethnographic, grounded theory or phenomenological studies. Although the framework approach underpinned data analysis, in order to make an informed choice a range of approaches and their purpose were considered including: content analysis; thematic analysis; phenomenological analysis; and grounded theory. Although these approaches are inductive and focus on meaning, they differ in their ontological and epistemological underpinnings and purpose (Morse and Richards, 2002). Content and thematic analysis focus on systematically exploring data to find common meaning; phenomenological analysis aims to capture the uniqueness of participants' stories as co-constructed with the researcher; and constant comparative analysis used within grounded theory, promotes theory generation (Patton, 2002; Crabtree and Miller, 1992). Other approaches such as discourse or conversation analysis are socio-linguistic in that they focus on the use and meaning of language and are rooted in the discipline of ethnography, which was not congruent with the aims of this study (Smith and Firth, 2011).

Thematic analysis is the most widely used approach to qualitative data analysis (Braun and Clark, 2006). Thematic analysis, like the framework approach, is gaining popularity within nursing and health psychology research settings, because of the increase in adopting descriptive designs to underpin qualitative research (Swallow *et al.*, 2011; Tierney *et al.*, 2011). Both approaches are flexible because they can be adopted across qualitative research paradigms and are suitable for analysis of different types of data and guide the analysis through a series of interconnected stages adding to the transparency of the analytical process (Patton, 2002; Pope *et al.*, 2000). These methods can provide rich insights into complex phenomena and be applied across a range of theoretical and epistemological approaches (Braun and Clark 2006; Spencer *et al.*, 2003b). However, thematic analysis has been criticised for lacking depth, fragmenting data, being subjective and lacking transparency in relation to the development of themes, which can result in difficulties when judging the rigour of the findings (Smith and Firth, 2011; Attride-Stirling 2001).

The framework approach has similar underpinning assumptions as grounded theory, in that data analysis may generate new theories, but the focus of framework approach is to describe and accurately present participants accounts to explore a topic that has received little attention (Ritchie and Spencer, 1994). The framework approach offers a systematic approach to data analysis through distinct but interrelated stages, allowing the researcher to move iteratively through the data until a coherent account emerges (Johnston *et al.*, 2011; Rabiee, 2004). This method was adopted to underpin data analysis because it offered clarity, guided a novice researcher and assisted in ensuring a clear audit trail was maintained and consequently ensured greater transparency in the development of the findings (Ward *et al.*, 2013; Smith and Firth, 2011; Srivastava and Thomason, 2009; Pope *et al.*, 2000). The framework approach facilitates cross-sectional data analysis (Smith and Firth, 2011); allows for between-case and within-case analysis comparisons and associations (Swallow *et al.*, 2011; Ritchie and Lewis, 2003; Snape and Spencer, 2003; Spencer *et al.*, 2003); and in-vivo codes promote the authenticity of the data (Ritchie and Lewis, 2003). Indeed within this study such a systematic approach allowed the child and parent data to be analysed separately then child-parent dyad, where relevant, to be combined in the final analysis to

identify similarities and differences between emerging themes (Furber and McGowan, 2011).

The interconnected stages of the framework approach guided data analysis as a systematic and transparent process (Swallow *et al.*, 2013; Ward *et al.*, 2013; Ritchie and Lewis, 2003; Popes *et al.*, 2000). Consistent with the framework approach data collection and data analysis were undertaken simultaneously facilitating the recognition of data saturation (Smith and Firth, 2011). The stages of framework are located with three discrete but interconnected stages: data management (coding the transcribed data to form an initial category); descriptive account (refining the categories and themes to develop more abstract concepts); explanatory accounts (reflecting on the associations and patterns within the core concepts). The three inter related stages of the framework approach are now presented:

- ***Data Management***

Although data management is time consuming it is an essential stage of the analysis and commences with transcribing the interviews verbatim. Data management involves condensing the data into manageable units, initially using the participant's own words (in-vivo code). Each interview was transcribed to facilitate familiarity with the data which also facilitated preliminary analysis by annotating transcripts with memos recording initial thoughts (Ward *et al.*, 2013). Codes were summaries of a phrase or paragraph from the transcript, which are linked together to form initial categories. Categories in turn form a coding index that is used as a means of organising the whole data set.

- ***Descriptive accounts***

Descriptive accounts involved reviewing the data within each category in the coding index, summarising and synthesising the categories, identifying links between the categories and ascertaining if categories could be grouped into an overall theme. The final stage of the data analysis makes associations across the data sets. Refining the categories and themes was an ongoing process throughout data analysis, which as the process evolved led to develop more abstract concepts leading into the conceptual framework. Within the study findings typologies of parenting styles emerged from the descriptive accounts of data analysis, *'Typologies are specific forms of classification that help to describe and explain the*

*segmentation of the social world or the way that phenomena can be characterised or differentiated'* (Ritchie and Lewis, 2003:p214). Family specific maps are presented in Chapter 6, Section 6.1.1 to illustrate cases representing three of the four different parenting style groups (Maccoby and Martin, 1983; Baumrind, 1967). All of the parents fit within one discrete parenting style.

- ***Explanatory accounts***

Explanatory accounts involve reviewing and constantly refining the original themes and categories, reflecting on the original data and the analytical stages, reflecting on associations and patterns within the core concepts to describe the decision-making between the child and the parent in relation to the management of childhood asthma and to seek wider application of the core concepts (Ritchie and Lewis, 2003). Explanatory accounts are constructed by the researcher by reflecting on the original data, identifying the emergent patterns within that data in order to produce a coherent account, interpretation and explanation of participant accounts (Srivastava and Hopwood, 2009).

#### ***4.8.1 Application of the framework approach to child and parent findings***

Codes were developed by summarising units of data (key words, phrases or sentences) from the transcript using children and parents' own words. Each unit of data was summarised to form an initial category. A list of categories formed the coding index that was used as a means of organising the whole data set. Ongoing records of preliminary thoughts and development of initial categories were maintained. An example of the coding matrix, of a child and parent individual interview transcription, highlighting the processes involved in identifying codes and initial categories is presented in Appendix 12 and 13 respectively. As the coding progressed similar categories were grouped together forming initial themes. The initial categories and initial themes formed the coding index. The process was undertaken separately for the child and parent data, Appendix 14 and 15 respectively.

Data management could have been managed using computer software such as NVivo® Version 10, Microsoft Excel (Swallow *et al.*, 2013) or Microsoft Word (Furber, 2010). Qualitative data software packages are not a pre-requisite for undertaking qualitative

analysis and have been criticised for extensive coding and categorising, resulting in data becoming unmanageable with the analysis becoming a reductionalist rather than interpretive process (Morrison, 1998). An initial attempt at using NVivo® Version 10, proved unproductive due to lack of familiarity with the software and learning the system hindered the ability to make links when developing codes. Consequently, a database spread sheet was used, enabling related codes to be viewed simultaneously. Using printed version of the coding matrix and coding index facilitated by the use of post-it notes to write initial categories and themes assisting with the iterative process of the analysis by moving post-it notes around, as the categories and themes were refined, combined and developed (Ward *et al.*, 2013). Using the spread sheet enabled the supervisors to be provided with anonymised transcripts for independent coding, which enabled decisions to be challenged and added to the depth of data analysis (Ward *et al.*, 2013). In addition coding and annotations were included alongside interview extracts, which facilitated discussion during supervision meetings. As data coding of the transcribed interviews progressed the coding index was refined. Similar codes formed initial categories. The categories were refined and similar categories formed initial themes. The refined categories and themes were used to sort and organise the whole data set and is presented in Appendix 16 and 17 respectively. Findings were contextualised by exploring the relationship between the final concepts and the established literature and theoretical perspectives related to child-parent shared decision-making of asthma management.

#### **4.8.2 Data reduction**

The data coding was a lengthy iterative process and was particularly challenging during the data management phase; progress was eventually achieved by moving away from a 'nursing lens' to a 'researcher lens'. Refining the categories and the themes as an iterative process is important to establish the credibility of the findings (Ritchie and Lewis, 2003). The four interview transcripts were used to develop the coding index and were independently reviewed by both research supervisors. An initial list of the child and parent data generated 69 and 55 categories, respectively. The child and parent categories were grouped thematically into 40 then 28, initial categories, respectively. Links between categories were identified and refined into 10 and 13 child and parent themes. Three child and three parent

core concepts emerged from the 10 key child and 13 key parent embedded themes. The coding index was reviewed on several occasions, reducing the biases through the exploration and discussion of different interpretations within the data. The study objectives were constantly referred to during this stage of data analysis, to remain focussed on the study aims. Two data sets were created: child and parent. As there was only one joint parent interview, this was included as one parent interview, although quotes are presented in Section 5.3. from both. Transcribing data verbatim enabled the analysis to remain close and true to the participant's own words, (Sandelowski, 2000), increasing the credibility of the research findings (Speziale and Carpenter, 2005). To capture the diversity of participant perspectives a range of quotes are presented (Spencer *et al.*, 2003). A particular strength of the framework approach is to enable transparency between the participant perspectives and the researcher interpretations (Morse and Richards, 2002), promoting the credibility of the findings. Regular discussions and reviews with both supervisors ensured the data analysis remained focussed on the child and parent perspective of shared decision-making for the asthma management. The application of critical thinking to how the child and parent description were coded, the links between the codes and categories and between the categories and themes, required nurturing and developed as the data analysis progressed. The explanatory accounts were contextualised by exploring the final themes with the theoretical perspectives (Chapter 2) and existing literature (Chapter 3). A service user day is planned to confirm concepts and themes are an accurate reflection of child-parent shared decision-making for asthma management. Dissemination of findings has primarily been through local, national and international conferences, outlined in Chapter 9, Section 4.

#### **4.9 Ethical Issues**

Favourable ethical approval to undertake the study was obtained from the National Research Ethics Service Committee North West-Liverpool East Paediatric Panel (REC Ref: 11/NW/0783 on the 3<sup>rd</sup> January 2012); Site Specific Research and Development approval with the participating NHS Trust between the period of 9<sup>th</sup> January 2012 and ending initially on 30<sup>th</sup> March 2013 but extended to 31<sup>st</sup> May 2013 (REC Ref: 11/NW/0783 on the 9<sup>th</sup> January 2012; 12<sup>th</sup> April 2013) and the College of Health and Social Care Research, Innovation and

Academic Engagement Ethical Approval Panel (Ethics Application: HSCR11/21 on the 18<sup>th</sup> January 2012). As the researcher was working with children an Enhanced Criminal Record Bureau disclosure was also obtained (Disclosure Number: 001343222070 on the 9<sup>th</sup> November 2011). Favourable ethical approval was granted on the first application and enabled the study to proceed.

All process and ethical considerations were guided by the recommendations from the British Psychological Society (BPS, 2010), The Royal College of Nursing Research Society (RCN 2011) and the National Research Ethics Service (NRES, 2011). Data storage was in accordance with the Data Protection Act (1998). To maintain confidentiality the participants were addressed by a pseudonym (Nicol, 2008), enabling all transcripts, demographic sheets and other identifiable documents to remain anonymous. The United Nations Convention on the Rights of the Child identifies the child's right to a name as particularly relevant (UN, 1989). Key ethical issues relating to the study were maintaining children and parent rights, treating children and parents with respect to their needs, ethical engagement with families and maintaining confidentiality.

#### **4.9.1 *Maintaining participant rights***

Children and parents were provided with the information sheets at least 24 hours prior to any interview, allowing individuals' appropriate time to consider their involvement with the study. They were advised to take the forms home, to read through thoroughly or to provide the opportunity for another individual to read it to them, giving them time to make an informed decision before contact was made by the researcher (RCN, 2011). If a child or parent did not wish the interview to be audio-recorded detailed field notes would have been taken but this was not necessary. If any participant became distressed during the interview the audio-recording would have been stopped, the child or parent would have been asked if they required a break and if needed re-scheduled the interview or asked they if they wished to withdraw from the study. In the event of a child becoming distressed support would have been sought from their parent, again this was not required. Audio-recording the interviews enabled the researcher more time to focus on the child and the parent without the distraction of making extensive notes (Balen *et al.*, 2000).

Consent may be obtained from the child, if the health care professional or researcher perceives the child competent to provide that consent (Danby *et al.*, 2011; Alderson, 2007; Mauthner, 1997). Therefore, the competence of the child as an informant needed to be established (Danby, 2002). If the child was perceived by the researcher to have the cognitive ability to understand the purpose of the study, the child and their parent each provided written consent. There were four levels of competence assessed: the first involved the individual being able to understand the information; the second the individual being able to retain the information; the third to consider the information and make a reasoned choice; and the fourth to make a voluntary and autonomous decision (Alderson, 2007). Prior to the interview the child was asked for their interpretation of their participation within the study to enable consent to be obtained. All of the children were able to fulfil the four levels of competence and explain the purpose of their participation.

It is important children are not coerced into participating in the study and potential difficulties may arise if the parent gives consent and the child is reluctant (Alderson and Morrow, 2004). If the gatekeeper such as a parent has already provided consent for participation within the study, due to the unequal power relationships, the child may find it difficult to refuse consent (Backett-Milburn and McKie, 1998; Mayall, 1994). If the child did not want to participate then their wishes were respected, irrespective of whether their parents wanted them to participate (Richards and Morse, 2007). A final check was undertaken immediately prior to an interview taking place, to ensure written consent had been received. In addition, child and parent verbal consent was obtained again and participants reminded that they were free to withdraw from the study at any time, without giving a reason and their care would not be affected. Each child's willingness to participate was monitored throughout the interview by observing the child's (and parent) verbal and non-verbal signs of willingness to continue (BPS, 2010).

#### **4.9.2 *Treating children and parents sensitively and with respect***

Interviewing has the potential to cause disruption to the family, within the home environment. In this study obtaining the child and parent consent, verbal and written, was required to enable participation within the study (NRES, 2011). Although the risk to the child was not anticipated, it is important to be aware of potential distress that can occur when



emotive topics are being discussed. Therefore, debriefing and relevant leaflets were available, if required. The Asthma UK website ([www.asthma.org.uk](http://www.asthma.org.uk)) and the asthma helpline number (08457 010203) would have been provided if the participant required further advice and support from asthma specialist nurses (SIGN/BTS, 2013). Participants would have been advised to seek advice from their GP if they had further concerns regarding their asthma. None of these incidents arose whilst the interviews were being conducted.

#### **4.9.3 Ethical engagement with families**

A range of challenges present to the researcher when interviewing a family, which include that the researcher is self-aware, flexible and adaptable due to multiple interruptions that may occur within a busy household ensuring interruptions are kept to a minimum (MacDonald and Greggans, 2008). All family members are affected, due to the study impacting on privacy and space within the family home (MacDonald and Greggans, 2008). There are advantages to interviewing the family within their own home: a safe and comfortable environment is provided (Williams *et al.*, 2007); the balance of power is shifted away from the researcher to participants (MacDonald and Greggans, 2008; Mayall, 1994). Children and parents were interviewed separately, as evidence suggests this is likely to increase the depth of data obtained from the child who may feel reluctant to express their own views freely in the presence of their parents (Gardner and Randall, 2012; Mauthner, 1997).

#### **4.9.4 Maintaining confidentiality**

Although the children and parents were considered competent to provide informed consent to participate within the study, it was made clear to the child and parent their quotes may be used within the thesis and publication but their responses would be anonymised. It was important the child knew any information provided would not be discussed with their parent (Hamilton and Hopegood, 1997). Although the issue of confidentiality was fully explained, with a clear explanation to the child, during the recruitment phase and prior to the in-depth interviews, incidents did arise during the fieldwork where parents attempted to either overtly or covertly enquire as to what responses their children had provided. The collection, storage and disposal of the data were kept in accordance with the Data Protection Act

(1998). All signed consent forms were stored in a locked filing cabinet and participants were given a study code, only the main researcher had access to this information. All the interview transcripts were anonymised.

Interviewing children raises additional confidentiality concerns (Fraser *et al.*, 2004). Any disclosure from the child that indicated they may be at risk or if the child was believed to be in imminent danger the relevant Designated Safeguarding Officer would have been notified ('Safeguarding Children and Vulnerable Adults policy' (v4) 20<sup>th</sup> January 2011). Eight years of school nursing and working in parallel with social services meant I was alert to child protection issues. However, if a disclosure had been made I was fully aware of my researcher role and would not have overstepped the professional boundaries.

#### **4.10 Summary**

A qualitative descriptive approach is congruent with the aims and objectives of the study without the potential constraints of adopting the lens of one particular methodology (Sandelowski, 2003; Holloway and Todres, 2003). This enabled a detailed exploration of child-parent shared decision-making for the management of asthma enabling the objectives of the study to be achieved (Patton, 2002). The design of the study enabled the researcher to undertake separate in-depth interviews for children and parents; and represent both shared and individual perspectives on the decision-making process and ensure the child's voice was given equal significance (Hopwood and Tallet, 2011; Ritchie and Lewis, 2003; Morse and Richards, 2002); to remain true to participant's own words (Sandelowski, 2000); allow data to be co-constructed between participants and researcher (Petty *et al.*, 2012; Speziale and Carpenter, 2005); and a flexible and naturalistic plan of inquiry (Paterson and Morin, 2012; Sandelowski, 2000). The framework approach provided structure to the analysis, fostering transparency of the data findings and interpretations, provided an audit trail enabling the reader to make their own interpretations of the findings (Ward *et al.*, 2013; Johnston *et al.*, 2011; Swallow *et al.*, 2011; Srivastava and Thomason, 2009). The development of a coding index within the data management stage of the framework model of analysis enabled data to be compared and contrasted between interviews (Huberman and

Miles, 1994). This qualitative descriptive study acquired grounded theory and ethnographic casts in the form of developing a conceptual framework from the findings and obtaining the meanings and actions from the child and parent participants within their natural environment, using in-depth interviews to collect data, instead of focus groups and observation traditionally employed within the methodologies respectively (Sandelowski, 2000). Chapters 5 and 6 present the child and parent findings.

## **5. Introduction**

The two main approaches to presenting qualitative data are interweaving the findings with established literature or presenting the findings and discussion separately (Richards, 2005). The latter approach has been adopted in an attempt to demonstrate transparency between participants' accounts and researchers interpretations and ensure the depth and richness of the participants accounts are represented (White *et al.*, 2003; Morse, 2002). Presenting the findings and discussion separately was an attempt to ensure the child's voice within the data remained prominent, which underpinned the philosophy of the study. This is particularly salient as there is a paucity of research specifically exploring child-parent shared decision-making for asthma management from the child's perspective, not the parent's representation of the child's perspectives.

The study findings are presented in two chapters. Who, what, why and when decisions are made is the focus of this first findings chapter, with data compared and contrasted within and across child-parent dyads, exposing child and parent perspectives with respect to decision-making concerning asthma management. The subsequent findings chapter (Chapter 6) presents examples of influencing factors and contextual situations where decisions shift and fluctuate between a child and their parents.

### **5.1 Participant characteristics and recruitment**

The sample consisted of 17 participants: eight children, seven mothers, one father and one grandmother (who was the child's main carer), recruited from twenty two asthma clinics. Although one of the main carers was a grandmother, for the purpose of the thesis, the main carer will be referred to as the parent. A second father came forward and then chose not to participate within the study. Children were between seven to eleven years of age. The goal

of purposive sampling frame was to ensure participants represented a range of perspectives, which was achieved. The characteristics of participants are presented in Table 12.

**Table 12: Child and parent characteristics**

Child characteristics		(n= 8)
<i>Gender</i>	Male: Female	3:5
<i>Age (years)</i>	7 years	1
	8 years	2
	9 years	1
	10 years	1
	11 years	3
<i>Age asthma diagnosed</i>	0-2 years	3
	3-4 years	3
	5-6 years	2
Parent characteristics		(n= 9)
<i>Relationship to the child</i>	Mother	7
	Father	1
	Grandmother	1
<i>Ethnic group</i>	White British	9
<i>Highest Qualification</i>	None	1
	GCSE/CSE/O Level/A level	2
	Degree	4
	Higher Degree	2
<i>Socio-economic classification</i>	1 – 3	4
	4 – 6	3
	7 – 8	2
<i>Employment status</i>	Full time	2
	Part time	5
	Full time carer	1
	Registered disabled	1

Social class was identified using the UK National Statistics Socio-economic Classification based on occupation (2000). Participants' socio-economic classification ranged from social group 1 (higher management) to social group 8 (long term unemployed).

Despite sustained effort over 12 months and visibility of the researcher within asthma clinics in an area of high South Asian community the study participants recruited were white British

children and parents. Recruiting participants from minority-ethnic communities is known to be particularly challenging when English is not their first language and potentially different cultural beliefs (Gordon *et al.*, 2010). Only one father from an ethnic minority background was keen to participate, unfortunately his daughter refused. Children are active agents and competent to make decisions that affect them so her wishes were respected (Skanfors, 2009). Although at the time this decision felt right, prioritising the child's voice was the focus of the study, in hindsight this may have been a lost opportunity and the father could have been interviewed.

Recruiting children and their parents was problematic, but failure to attend scheduled clinic appointments provided a further barrier to recruitment. The purposive sampling approach within out-patient clinics relied on parents taking responsibility for their child's attendance at clinic. However, across the different outpatient clinics there were approximately 170 episodes of non-attendance per month. To overcome recruitment barriers in the future a different setting could be used such as school, enabling the children that would like to participate, a 'voice' within decisions that affect them. Indeed to capture ethnic minority families a community setting employing the services of an interpreter, to overcome the language barrier and facilitate the cultural differences, would be more appropriate.

## **5.2 Study Findings: who, what, when and why**

Exploring whether children or their parents made asthma management decisions, what those decisions were, when and why the decisions took place, four core concepts and themes by both children and parents were exposed:

1. Making sense of asthma
2. Independent decisions
3. Control and responsibility
4. Decision preferences

Each core themes are explored in more detail presenting direct extracts from the original data, enabling the reader to make their own judgements on the researcher's interpretations

and bring the data to 'life' (Holloway and Wheeler, 2002). Facilitators and barriers to child-parent asthma management decision-making are weaved throughout the themes, such as knowledge and understanding, self-confidence, cognitive development, school, locus of control, confidence in child's ability, parenting styles and preferred decision-making.

### **5.3 Making sense of asthma**

Children identified making sense of asthma as essential to their developing the knowledge and skills to self-management of asthma. As the child achieved greater understanding and experience, there was for most children greater participation within the decision-making process of their asthma management. The core concept of 'Making sense of asthma' included two similar themes and two different themes for both children and parents:

- Understanding asthma and treatment
- Recognising and responding to asthma symptoms
- Recognising and responding to asthma triggers
- Teaching the child to listen to their own body

#### **5.3.1 Understanding asthma and treatment**

Children as young as seven years of age were able to identify the illness symptoms they experience and their association with asthma. The most common symptom described by the children was coughing, especially a night cough. Children also described in-depth symptoms of wheezing and feeling tightness in their chest.

*'I get a cough, of course...I think I have had asthma since I was 8...I have been coughing all my life though...each day I am coughing' Sally 11*

*'...the warning signs are wheezing' Dean 7*

*'An early warning sign is that when you start to see something that ...if you are bad coughing all the time and if I don't know. A cough is one of the first things and your lungs hurt a bit more. I think that is one of the early warning signs' Nathaniel 11*

*'I know my asthma is starting up by coughing...' Amanda 9*

*'...at night sometimes I start to cough' Alicia 10*

*'...coughing and started wheezing' Nicole 11*

It is from these experiences of asthma symptoms over time that their understanding of asthma and the treatment develops. The children demonstrated an understanding of their medication the majority used differentiating between different inhalers through colour for the different ways they need to be taken and why.

*'I have got a purple inhaler in my room which is the one I take in the morning and night' Dean 7*

*'I have got 2 of them a brown one and a blue one but I can't remember their names though...the preventer is the brown one (inhaler) you have each morning and night... I don't like taking the blue one (inhaler) cos it is not very nice. It tastes of frogs. I take that when I need it' Nathaniel 11*

*'I take my blue one when I am chesty and my brown one is for everyday' Julie 11*

*'I take my blue one 20 minutes before exercise and the brown inhaler is in the mornings and nights' Nicole 11*

Having other children in the class at school gave one child an understanding of the different severity of asthma.

*'In the class there are 3 of us that have asthma but one of my friends has really bad asthma and she has another colour of inhaler which I don't know and she gets loads of days off school cos she is always ill. My other friend you never see her taking her inhaler cos I think she had a cough one time and they said it was asthma but I don't think it is.' Nicole 11*

### **5.3.2 Recognising and responding to asthma symptoms**

Recognising and responding to asthma symptoms was the start of the children learning about asthma and how asthma impacts on their health and daily activities. The descriptions of symptoms usually highlighted a response of using their inhaler.

*'Signs are wheezing, chest is beating really fast and I get a stitch in my heart... need my inhaler' Dean 7*



*'...get a bad cough...your lungs have a bit of pain...cough is one of the first things and your lungs hurt a bit more...I had my inhaler and it (coughing) calmed down a bit'*

Nathaniel 11

*'My chest sometimes feels full of mucous...I start coughing so I have my blue inhaler'*

Julie 8

*'I had a bad cough and started wheezing...I get dizzy and shaky and I get a sore throat, probably cos I cough so much... kept coughing and started wheezing...take my inhaler'* Nicole 11

*'I think she realises her inhaler is going to make her feel better as opposed to not having the inhaler.'* Kirsty, mother of Amanda 9

Dean indicated that sometimes he didn't remember to take his inhaler and didn't recognise when he was wheezing and he needed prompting by his mother, who confirmed this.

*'... don't always remember to take my inhaler, don't know why... I can't feel myself wheezing but mum might just see me like puffing she will say do you want your inhaler and I will say yes.'* Dean 7

*'If Dean was coughing we would ask him if he needed his 'magic puffer'. If he is getting more chesty and it is a cold environment, he realises he hasn't taken his preventative inhaler'* Susan, mother of Dean 7

Children demonstrated a recognition not just that inhalers were required, but an understanding of their use to relieve symptoms or other strategies instead of using an inhaler. Dean through his comments demonstrated understanding different levels of symptoms and the action taken.

*'I know to take my inhaler when I start coughing and I feel bad'* Paul 8

*'My doctor changed my inhaler and that is why I am feeling better'* Alicia 10

*'Went to my friend's house and he has a hamster...I started coughing a bit so I took my inhaler...get a bad cough with asthma and to help reduce it you need an inhaler'*

Nathaniel 11

*'I needed it once (inhaler) and then I was kind of ok after a few minutes...when I do park running I usually take this (inhaler) and I take it 20 minutes before I do the exercise cos it opens the 'breath-ways'' Nicole 11*

*'When I start coughing sometimes I will get a drink and sometimes I will have a lozenge' Julie 8*

*'If it is just a little bit of wheezing I would go to school but if it is really bad like now, I won't go' Dean 7*

Paul and his mother both recounted times when he would identify experiencing symptoms and when playing football and stop or ask for his inhaler.

*'I stop playing football because of my asthma' Paul 8*

*'He would say I need to have a break or I need my inhaler or I need to stop now (playing football)' Sandra, mother of Paul 8*

### **5.3.3 Recognising and responding to asthma triggers**

Understanding, recognising and responding to asthma triggers was crucial to making informed decisions whether to modify behaviour to avoid or accommodate a trigger and/or take necessary action using an inhaler to prevent exacerbating the asthma.

*'...cos of his (dog) hairs I cough a bit. I just go to sleep' Nathaniel 11*

*'When I do PE I don't need my inhaler...when am dancing sometimes I need it (inhaler)' Alicia 10*

*'When I am in loads of heat...then I start coughing or because my grandma and granddad smoke...I start coughing' Sally 11*

*'My asthma starts up when I am doing sports and you are running round too much I get out of breath then I know to go and get it (inhaler) because I have been running round a bit too much' Dean 7*

*'If it is really windy when I am cycling sometimes I will lose my breath. I won't take my inhaler...the wind sometimes starts me coughing and...sometimes running makes me cough' Julie 8*

*'Dogs and guinea pigs make my asthma worse...and running sometimes...Sometimes just walking can start my asthma up'* Nicole 11

*'Well on trampolining I don't think that makes my asthma worse cos... I got a bit tired. I just got a bit of a cough and I only started coughing on my last go so I carried on with my lesson'* Nathaniel 11

Children could differentiate between a range of general triggers and triggers that directly influence their own asthma symptoms. Sometimes this resulted in them modifying their behaviour, so not running as fast, not running in cold weather and vacuuming dust regularly, so as not to exacerbate the asthma.

*'Nothing else makes my asthma worse. No, pets don't. but sometimes chasing the dog does but that is because I am running not because of the dog. Cold weather doesn't make me worse but it sometimes makes me a bit poorly but it doesn't make me wheezy'* Dean 7

*'Well there isn't a lot of things that sets my asthma off except from dust but that is only sometimes because we Hoover up a lot...Cold weather only makes my asthma worse but if I am walking I can stay outside there for ages'* Nathaniel 11

*'It is only after I am jogging I don't run out of energy after a long time I start coughing and if I run very, very fast from there to there I might run out of breath a bit. I would keep on going but I wouldn't run I would slow down a lot. I don't normally use my inhaler unless I really need it'* Nathaniel 11

*'My mum has a Wii and it is Zumba so I go dancing on it, so I stop for a few seconds catch my breath and then I carry on'* Sally 11

Or sometimes it resulted in them modifying their behaviour or taking action to remove the trigger, taking their inhaler to treat the asthma symptoms, but not necessarily avoiding the trigger, reinforced by parent comments.

*'I avoid touching the cat as it might start my asthma off. I just ask my dad to take the cat off my bed because it might trigger my asthma'* Alicia 10

*'My asthma starts up when I am doing sport...then I know to go and get it (inhaler)'*  
Dean 7

*'Her asthma does not impact a lot on her life. She would just go and look at the animals and then come home and say ooh, look at me wheezing. If ever she was on her own she would just take her inhalers and then let me know'* Jillian, mother of Nicole 11

*'She doesn't avoid specific triggers she just uses her inhaler if symptoms start following exposure to a trigger'* Jillian, mother of Nicole 11

Despite having symptoms when running fast and getting out of breath easily children valued participating in a range of sporting activities rather than avoiding exercise because it may trigger their asthma.

*'I like going bowling and I like doing tennis. I like playing instruments and I also like swimming. On Saturday I go trampolining I have just got my new award level 7. I like at school we do rugby and basketball... we do these tests where you have to go around in a circle in the room and you have to do different things like yoga and things like that'* Nathaniel 11

Through making sense of asthma and developing their knowledge each time they experience asthma symptoms a child begins to recognise and make decisions associated with specific triggers that influence their asthma. For example, children could rationalise continuing with leisure and physical activities even in the presence of illness symptoms because they could modify activities knowing this would alleviate symptoms. Some children had developed their own strategies for carrying on with what they wanted to do.

*'It is bad having asthma as you can't do a lot of sports without stopping for a couple of minutes to get your breath...I still enjoy running around...I would carry on doing it but not as fast'* Dean 7

*'I normally take a drink of water, stop for a couple of seconds then I will carry on running. I thought of that'* Sally 11

*'I stroke the dog and wash my hands after...sometimes I have to go away from the dog for it (itching) to settle down'* Nathaniel 11

Comments suggested that through experience children developed an awareness of asthma triggers rationalising whether to avoid these triggers or not, weighing up the risk of the impact of the trigger with the desire to undertake pleasure from engaging with the activity.

*'My dogs and cats don't start my asthma off. Even if they did I wouldn't get rid of them. I would put up with what I had to put up with cos I love dogs...I have dog hairs on me now. I just carry on and ignore it there are worse things in life'* Sally 11

*'I have an allergy to cats...and my grandma has 3 cats. The cats do not stop me going to my grandma's house'* Nathaniel 11

Potential challenges occurred for parents who want their child to participate in childhood activities and not appear different from their peers but also recognise the impact of triggers on their child's health.

*'His dad was worried about him playing football but I just think he has to live normally'* Sandra, mother of Paul 8

#### **5.3.4 Teaching the child to listen to their own body**

The importance of their child learning to respond to changes in their breathing and supporting their child to begin to develop independence in relation to responding to asthma symptoms and making treatment decisions was evident throughout the parental interviews. Parents confirmed the children's comments that they associated treatment according to colour; indeed they reinforced this teaching them the difference through colour, but were aware that some children may not fully understand the role of each inhaler, particularly the younger aged children.

*'He knows his blue inhaler relieves him but he probably doesn't know taking his prophylaxis keeps him well'* Sandra, mother of Paul 8

*'If she is coughing she might say I need my blue...'* Louise, mother of Julie 8

They identified teaching their child to listen to their body and try to make independent treatment decisions in relation to the symptoms, but sometimes the child may need a prompt or direction to help them learn and recognise the time to make a decision.

*'I normally remember to take it but sometimes I forget. Well my mum says it every day as well...have you taken your inhaler? If I haven't I will go up and take it'*

Nathaniel 11

*'She always starts with a runny nose and then a cough. She then gets a feeling in her throat, she has said that a few times...need to make them aware of what to do, she needs to be able to voice if there is a problem.'* Louise, mother of Julie 8

*'I will ask her if she has been coughing a lot at school and she will say yes. I tell her she needs her inhaler. I just think she forgets'* Louise, mother of Julie 8

*'I will say have you taken your medicine and usually it is yes...'* Muriel, grandmother of Sally 11

The contrasting comments from Dean and his mother, were interesting suggesting that he wasn't as reliable at taking his medication as his mother thought, even though he demonstrated agency and confidence in decisions he did not recognise some symptoms or did not fully understand the importance of regular preventative inhalers. Suggesting some messages and decisions needed reinforcing and monitoring.

*'He listens to his own body, he knows how he feels and he doesn't know it any other way'* Susan, mother of Dean 7

*'... I can't feel myself wheezing but mum might just see me like puffing she will say do you want your inhaler and I will say yes'* Dean 7

*'He knows what each inhaler is for. He knows his symptoms. He knows one is a preventative and one to take afterwards (asthma symptoms). We have always talked to him in terms of colour and the job of each'* Susan, mother of Dean 7

*'I don't always remember to take my medication... (laughing)...it is mainly in the mornings with my purple one. I don't know why I just walk past it. I keep it in my room in a little tub. Sometimes it just doesn't get taken. I don't start wheezing...I don't tell my mum when I have forgotten'* Dean 7

A daily routine can help children adopt and learn a pattern of taking regular preventative medication.

*'It is normal to him. He has his serotide every morning and night that is part of his routine'* Sandra, mother of Paul 8

*'In the morning when I get up I spray and then I do that at night'* Sally 11

*'Even from a young age we have tried to talk to him about his asthma and getting him to talk to us about his asthma and getting him into a routine...'* Jenny and Peter, parents of Nathaniel 11

#### **5.4 Independent child decisions**

After experiencing asthma symptoms in response to different triggers over time children are better placed to understand and recognise their asthma and make their own decisions regarding their asthma management. Indeed the children across the age range indicated and described autonomous decisions-making for a variety of aspects of asthma management. Table 13 presents an overview of each of the child participants, their age, age of asthma diagnosis (obtained this information from the parent) and the type of independent decision reported.

Dean, seven years old with an asthma diagnosis of four years demonstrated a similar or higher level of responsibility for asthma management decision-making compared with Sally aged 11 years with an asthma diagnosis of over nine years. The age range of the child and the duration since the asthma diagnosis did not appear related to their level of autonomous decision-making within this group of children. Independent decisions were made for a range of management tasks, which included: deciding to use reliever and preventative inhalers; deciding to avoid or not, specific asthma triggers; deciding recognised asthma symptoms required treatment; deciding to administer or not reliever inhaler in the presence of symptoms; deciding to minimise physical activity in presence of symptoms, deciding to resume physical activity following onset of asthma symptoms (Table 13).

**Table 13: Child characteristics and decision examples**

<b>Child / Age yrs</b>	<b>Age of diagnosis</b>	<b>Time since diagnosis</b>	<b>Independent decision examples</b>
<b>Dean 7</b>	3 years	4 years	Decides when to administer reliever and preventative inhaler, decides asthma symptoms require treatment, decides when to restrict physical activity
<b>Paul 8</b>	1.5 years	6.5 years	Decides when to administer reliever inhaler, decides asthma symptoms require treatment, decides to cease physical activity in presence of asthma symptoms
<b>Julie 8</b>	1.5 years	6.5 years	Decides when to administer reliever and preventative inhaler, decides not to avoid specific triggers, decides whether asthma symptoms require treatment, decides to not always administer reliever inhaler in presence of symptoms
<b>Amanda 9</b>	4 years	5 years	Decides to minimise physical activity in presence of symptoms, decides asthma symptoms require treatment
<b>Alicia 10</b>	3 years	7 years	Decides when to administer reliever inhaler, decides asthma symptoms require treatment, decides to avoid specific triggers, decides when to resume activity
<b>Sally 11</b>	1.5 years	9.5 years	Decides when to administer reliever inhaler, decides asthma symptoms require treatment, decides not to always administer reliever inhaler in presence of symptoms, decides to take action to relieve symptoms
<b>Nathaniel 11</b>	5 years	6 years	Decides when to administer reliever and preventative inhaler, decides not to avoid specific triggers, decides whether asthma symptoms require treatment, decides to not always administer reliever inhaler in presence of symptoms
<b>Nicole 11</b>	5 years	6 years	Decides when to administers reliever and preventative inhaler, decides not to avoid specific triggers, decides asthma symptoms require treatment

The majority of children made an independent decision when to use their inhaler whether this was at home or at school. Dean indicated that he made more independent decisions about his asthma management when he was at his dad's house (parents separated).

*'Yes I know what a decision is. I make the decision to use my inhaler'* Nicole 11

*'I decide myself and take my inhaler if I need to'* Nathaniel 11



*'Mostly I remember to take my inhaler in the morning but it isn't like I would have an asthma attack if I didn't...The last time I had an asthma attack was at school...One of my friends ran upstairs and got the inhaler and I took it' Nicole 11*

*'At school you have to ask miss because you're not allowed in on your own so if you wanted your inhaler you would go and ask miss but if you didn't and you was alright you would just carry on. Yes, I would make that decision at school' Dean 7*

*'When I go to my dad's if he thinks that I need it I just stop cos my legs are aching. No I haven't taken my inhaler because I am ok. I have just got a bit of pain in my legs so I carry on doing it. Even though my dad wanted me to take the inhaler I don't' Dean 7*

Nathaniel identified how his response to asthma had definitely changed as he has grown up and become more independent.

*'I would sit down and wait for someone when I was little. Now I am 11 I would either go to my mum if I don't have my inhaler with me or there wasn't one close but normally I have one with me so I would just use it then' Nathaniel 11*

Decisions were made to carry on an activity in the presence of an asthma symptom but children decide to independently modifying their behaviour, also demonstrated earlier in the responding to symptoms and triggers. Often after making an independent decision they notified their parent of their action.

*'I keep up with other children... I start coughing and if I run very, very fast. I would keep on going but I wouldn't run I would slow down a lot. I don't normally use my inhaler unless I really need it' Nathaniel 11*

*'If I had been coughing and wheezing sometimes I might go back out and play or I might just sit and watch TV...I make that decision' Alicia 10*

*'I still enjoy running around and it doesn't stop me doing it. I would just do it and if I needed my inhaler I would just go in and get it and then I would go back out. I would carry on doing it but just not as fast so it wouldn't stop doing it' Dean 7*

*'Sometimes I use the one in my bedroom if I am really like coughing really badly other times I might take two puffs and sometimes I might take one puff and then I will let my mum know that I have done it' Dean 7*

*'...so I go dancing...I stop for a few seconds, catch my breath and then I carry on' Sally 11*

But Sally aged 11 and Amanda, 9 and Julie 8 were not as independent as others in their decision-making although there were some comments from Sally and Julie that suggested they had a degree of independent decision-making or it was developing or they lacked self-confidence.

*'You will have to ask my grandma that. I have no idea how often I use my inhaler...mostly I remember to take my medication on my own' Sally 11*

*'I sometimes don't like to make the decision because I could make the wrong decision, so sometimes I like grandma to help me make the decision' Sally 11*

*'If I was playing in my bedroom and I started coughing I would come down and tell my mum (not taking inhaler herself)...start coughing so my mum sits me down and brings my medicines out and gives me my blue inhaler' Julie 8*

*'There are times when I think I need my inhaler but my mummy doesn't cos she thinks I might have already taken it...so I just take it' Julie 8*

However the exchanges between Sally and her grandmother suggested she may make a decision to have her inhaler and ask her grandmother but be discouraged from using it as her grandma was under the impression the medication had side effects.

*'I will say 'you can have your medicine but you know it has side effects...try sitting down for a few minutes...' Muriel, grandmother of Sally 11*

This could undermine her confidence and be the reason behind her lack of decision-making. To compensate Sally developed strategies such as taking a drink of water or stopping catching her breath then carrying on to accommodate for this.

Out of all of the children Amanda aged 9 reported not really making any decision on her own but she demonstrated some degree of agency when reporting that her symptoms required treatment (even though her mother or teacher administered the inhaler) and she minimised physical activity in the presence of asthma symptoms.

*'I know my asthma is starting up by coughing. I don't know what else. I don't know what I do when my asthma starts up. If I was at school and my asthma started up then I would tell my teacher that I need my puffer. She would get it for me and she would do it. She presses it (inhaler) and I use the spacer'* Amanda 9

*'She normally holds the spacer and I put the inhaler there then she uses it with me watching'* Kirsty, mother of Amanda 9

Nathaniel found that discussing things as a family helped him make better decisions and become more independent.

*'We all discuss things together about my asthma. The good things are that if I forget well we all started to forget before but cos we have started talking about it and that I need to remember then I start to do it by myself, so makes decisions together helps me'* Nathaniel 11

### **5.5. Control and responsibility for decisions**

Taking a degree of control over their asthma management was observed within the independent decisions some children make whether to take an inhaler to prevent or relieve symptoms or remove themselves from the influence of triggers. Different environments and situations influenced the level to which children held the responsibility for the asthma management and/or whether the control over decisions was taken off them. These facilitators and barriers to decisions include; identifying and monitoring medication, access to their inhaler, conflicting opinions as to whether they need their inhaler and the environment in which they found themselves, particularly at school.

A child's ability to take responsibility and make independent decisions was increased when they believed they knew what they were doing, supported by parents who also believed in and trusted their children's ability to self-manage.

*'I know I am taking my medication properly because I can feel it going down my throat...the doctors at the hospital have shown me how to take the medication'*  
Nicole 11

*'In the morning when I get up I spray and then I do that at night. My grandma knows I know how to do it'* Sally 11

*'She is old enough, she is responsible enough. I think she can do it (asthma management)'* Muriel, grandmother of Sally 11

Parent comments of those children who demonstrated greater self-efficacy for their illness (Alicia, Nathaniel, Nicole and Dean) suggested they had a level of confidence in their child's ability to make a decision and therefore allowed them greater freedom to decide on how their asthma was managed, some suggesting that this had been a trial and error letting them increased responsibility monitoring and correcting problems.

*'She knows how she feels better than anyone'* Jillian, mother of Nicole 11

*'She has had it a big part of her life and she is just used to it (asthma). She knows she has got it (asthma) and she knows what to do if she doesn't feel so good. She is old enough to deal with it herself'* Lynn, mother of Alicia 10

*'She is very independent. She is in charge and mostly she remembers. She has been independent for about 18 months. We did trust her before but then found out she wasn't doing it (administering inhaler)'* Jillian, mother of Nicole 11

*'He is very organised, not like me. He is pretty good at controlling it (asthma) himself. He went through a period of losing them (inhalers) but he seems to have got over that now. He can cope with it himself'* Jenny, mother of Nathaniel 11

*'He organises himself well...he even organises us'* Susan, mother of Dean 7

Some children took on the additional responsibility of reporting when medication is low and identifying to their parents when they needed to order more.

*'At home I would let my mum know when my inhalers are running out'* Dean 7

*'When you shake it (inhaler) you can hear it. So sometimes you just press it and nothing comes out and then you can change it. I would let my mummy know if there was nothing in and then she gets me another brown one'* Julie 8

*'Yes, I always look when it is running out cos there is a little dial on the blue ones and when it is on red I always look at them but normally my mum gets them (inhalers) a bit earlier before they go'* Nathaniel 11

Those children that demonstrated greater confidence, independence and control for their asthma management had free access to their inhalers allowing them the ability to decide to take them when required, without having to ask permission.

*'He has his spacer and inhaler under his pillow he uses it and then lets me know '*

Sandra, mother of Paul 8

*'She has a puffer pouch that makes sure she has her inhaler with her'* Jillian, mother of Nicole 11

*'In the bathroom we have this ledge and on there is the inhaler...so I don't forget to take it'* Nicole 11

*'I have got a purple inhaler in my room which is the one that I take in the morning and at nights'* Dean 7

*'She will do it herself (make the decision)...she had a competition, a dancing competition and she said will you bring me my inhaler there...'* Lynn, mother of Alicia 10

Out of all the children Amanda aged 9 had the least responsibility and control for her asthma management decisions and she preferred to rely on others to take over, but she was aware when she needed her inhaler and able to notify people she was experiencing asthma symptoms. The lack of control and responsibility could be explained by Kirsty's comment that the responsibility for taking the inhaler as 'we' not that Amanda takes the inhaler indicating her control over the medication (explored in more detail in the next chapter).

*'I know my asthma is starting up by coughing. I don't know what else. I don't know what I do when my asthma starts up. If I was at school and my asthma started up then I would tell my teacher that I need my puffer. She would get it for me and she would do it. She presses it (inhaler) and I use the spacer'* Amanda 9

*'It's usually my mum that remembers to take them (inhalers)'* Amanda 9

*'Every morning we get up and have breakfast, teeth and we have our inhaler'* Kirsty, mother of Amanda 9

Often a child's control in decision-making was compromised in the school environment, as they were dependent on others to gain access to their inhaler. One solution by Nathaniel

was to hold their own inhaler in their bag at school and the school agreed, but for the younger children inhalers were kept out of reach.

*'My inhaler is kept in a box on the windowsill at school. The teacher sends you in to have it. I do it (administer inhaler) myself'* Paul 8

*'It was kept in a box in class where all the medical stuff is kept... If you wanted your inhaler at school, you would have to go and ask miss because you're not allowed in'* Dean 7

*'...usually I have it in my bag at school. I had my own inhaler from when I was in about year 4. I thought should I take my inhaler with me and my mum said yes and I asked a teacher and they said I could as well'* Nathaniel 11

Julie's mother indicated that Julie was often reluctant to take her inhaler at school as she does not like 'to be singled out', whereas others did not find it such a problem taking an inhaler in front of friends.

*'I don't mind taking my inhaler in front of my friends. They don't really help me but at my old school they did but I have never really had to go out of school at high school yet'* Nathaniel 11

*'I do my inhaler in front of my friends at school because I am not really bothered and they are not bothered'* Nicole 11

Nathaniel one of the oldest, with a strong sense of responsibility for his asthma described how sometimes his decisions are overridden, even when the parent indicates the child knows best there was evidence that they encourage them to take the inhaler against their wishes 'to be safe.'

*'Sometimes at bed time my mum always thinks I am wheezing but it is just cos when I go to sleep I make silly noises by accident. My mum wants me to take my inhaler but I say I don't think that I really need to but then she says just take it to be safe so I take it'* Nathaniel 11

## 5.6 Decision Preferences

There was a sense of preferred decision-making across the majority of children making decisions in response to symptoms and triggers highlighted throughout earlier sections, but at times these were independent at other times parent driven or shared. A number of comments from both children and parents identified that particularly surrounding the increasing severity of asthma symptoms the preferred responsibility for decision-making was securely with the parents, although the decision to involve parents was sometimes often initiated by the child.

*'I am happy with the decisions that I am involved with... I decide to involve my mum or dad if it is really bad but normally I would just have my inhaler'* Nathaniel 11

*'I only let my mum know if I have taken like two puffs if it is really bad...'* Dean 7

*'Sometimes when I have a bad cough and I am a bit shaky I will ask my mum if I should take my inhaler. She will say if you are wheezing or your chest is tight then I should and she kind of helps me to make that decision'* Nicole 11

Irrespective of a child's self-confidence and their level of independent decision-making children felt reassured by sharing decisions with their parents particularly when they were not feeling well.

*'Then it (coughing) got worse so I went to my mum and told her I had bad asthma and then she gave me my inhaler'* Nathaniel 11

*'If it (asthma) was really bad and I had taken my inhalers, then I would go and wake my mum up'* Nicole 11

*'I just walk across the landing and walk in to my grandma's bedroom. Grandma doesn't like waking up during the night so if I have a problem I will tap on granddad'* Sally 11

*'When I got whooping cough and my asthma cough started I got wheezy, so I did not go out for five weeks then I asked my mum if I could play out'* Dean 7

Nathaniel described a situation where his symptoms were severe and he requested to go to hospital and shared the decision with his mother.

*'I had to go to hospital but it was because I had a bad cold... the teacher said are you ok and I said yes then later on she said would you like to go home and I said yes please cos I was a bit pale as well. We went to my house with my mum and we waited a bit but it got worse so we went to the hospital. Well I asked my mum first to go to the hospital and she said yes we will just wait a bit and then she said we should go. So, I asked to go to the hospital'* Nathaniel 11

There were strong views from parents that when the symptoms were severe they were in control of the decisions, irrespective of their child's wishes, others shared decisions but still offered more direction.

*'We would involve Dean...unless I felt this was more. It would be my decision if we were going to the hospital. It is my decision if he has time off school due to his asthma. Obviously if he was having a bad asthma attack, I would take over, regardless of what Dean wanted'* Susan, mother of Dean 7

*'It is normally me that wakes during the night and I will just give her her inhalers. I don't ask her I will just give it to her because I don't want to go back to the situation where she is in hospital. If she doesn't feel well then I will go into school and tell them to up her inhalers'* Kirsty, mother of Amanda 9

*'We usually agree on her asthma management but we don't always agree on other things. She would usually bring the 'rasp' to me I would just tell her she has to have it (inhaler)'* Jillian, mother of Nicole 11

Parents described how they support their children when disturbed in the night or they are experiencing severe symptoms by keeping them close often sharing a bed to ensure they are safe.

*'Well when he had woke me up to say he needs his inhaler I would probably just sit with him for a while to see if it is a little bit more'* Sandra, mother of Paul 8

*'She sleeps in the same room then we can get some sleep'* Kirsty, mother of Amanda 9

*'I always take Julie into my bed if there is a problem with her asthma'* Louise, mother of Julie 8



*'He doesn't usually have symptoms during the night but he would just shout if he needed me'* Jenny, mother of Nathaniel 11

Julie recognised that making a decision with her mother helped her learn how to better manage and make decisions, especially in situations when her mother was absent and she needed to make a decision by herself. Louise (Julie's mother) highlighted that she would remind her and helps her at home to make decisions.

*'I like making decisions with my mum cos I love her ...it helps me make decisions when I am at school'* Julie 8

*'She knows I will remind her at home'* Louise, mother of Julie 8

Indeed other children identified similar support and reassurance at home preferring to share decisions with their mother (or grandmother), who in all family dyads was the primary decision-maker with respect to asthma management other than the child themselves.

*'My mum helps me to care for my asthma. If I start coughing my mum will go and get my inhaler. If I start coughing and wheezing I will come in and ask my mum if I can have my inhaler. I also ask my mum if I can go back out and play'* Alicia 10

*'Yeah maybe she has more responsibility when she is at school and more responsibility at her Dad's but when she is with me then I probably help her out more than anyone else would...'* Lynn, mother of Alicia 10

*'I would make that decision myself (inhaler use) at school but at home mum would help'* Dean 7

*'I like sharing decisions with my mum because otherwise I would forget to take it and I wouldn't take it'* Dean 7

*If I was playing in the bedroom and started coughing I would come down and tell my mum but by myself I might just have my puffer'* Julie 8

Dean's mother Jenny summed up the importance of the child understanding and being able to make independent decisions regarding their asthma management.

*'As he gets older I am with him less and less, he needs to know how to manage his asthma'* Susan, mother of Dean 7

This was a stark contrast to how Amanda aged 9 preferred her mother to make all the decisions.

*'Mum makes all the decisions about my asthma. I don't want to be involved in any decisions'* Amanda 9

Similarly Sally referred often throughout her interview that her grandma could answer that question and she knew all about it more than herself suggesting a reduced confidence in her own ability or alternatively a preference not to be burdened with the responsibility of her asthma management at this time.

*'You will have to ask my grandma that. I have no idea how often I use my inhaler'*  
Sally 11

The different preferences and experiences suggest different factors are influencing the time frame it takes children to take a more leading role in decision-making, irrespective of age Sally 11 compared with Dean 7 or length of diagnosis 9.5 years compared with 4 respectively. Interestingly Sally's grandma highlighted the need to give children more decision-making responsibility, but not young children so the control may not have been given to Sally earlier than now and her skills and confidence are just developing.

*'I am there for her but I am not on her back. I will say have you taken your medicine and usually it is yes...It would be different for a young child but you have to give her some responsibility'* Muriel, grandmother of Sally 11

There were preferred levels of engagement with health care professionals with those children demonstrating a higher self-confidence and independence engaging with doctors and discussing their care and others not wanting to be involved leaving the decision-making with their parent.

*'I talk to the doctor at the clinic. It is usually my mum cos my dad is always at work but it depends who is there. My doctor is really surprised that I can play the oboe because it is the hardest instrument in the world'* Nathaniel 11

*'I talk to the doctor but I can't remember what about. They just ask me a few questions like how am I feeling and things like that and my mum tells them how I am*

*doing with my cough and my asthma. I sometimes give them the answers but sometimes I need my mum to help me a little bit'* Dean 7

*'... (laughter) I don't know who I see at the hospital. These are the questions that you should be asking grandma'* Sally 11

*'I talk to the doctor when we go to clinic. Well the doctor kind of like talks to me and they ask me lots of questions and I answer them and if I was having any trouble with them then my mum will help and remind me then I will carry on talking to the doctor'*

Nicole 11

*'Mum talks to the doctor or the nurse at the hospital. I don't want to talk to them'*

Amanda 9

Some parents felt they had a better understanding of their child's asthma that they could make better decisions than health care professionals. Sally indicated not taking the advice of the professional to carry her inhaler with her.

*'I know I can make a right decision for my child because he is my son. I feel I am best placed to make decisions not the health care professional'* Sandra, mother of Paul 8

*'She (doctor) said always have your inhaler in your drawer just in case...I don't have my inhaler in school. I don't need to take it...I don't have an inhaler with me when I am playing out. I would just have a drink of water if I start coughing'* Sally 11

There was certainly an impression that the health care professional could engage better with children and involve them in the management decisions but whether they engaged was dependent on their parents and the child's self-confidence. With Sally's grandmother reluctance to encourage inhaler use to reduce the impact of side effects highlighted a need for health care professionals to periodically clarify the parents and carers knowledge to avoid misunderstanding impacting on a child's asthma mismanagement.

The findings identified the child's perceived benefits of sharing the decisions and the support required in the decision-making process. Children's accounts highlighted that they often seek affirmation from parents about treatment decisions for example after administering medication. This reassurance is important because children may not necessarily share the decision-making but want to share the responsibility of the decision with parents. This

sharing of responsibility appears to relate to the child's confidence and control of their decision-making ability and is not age related. Parents retained or regained responsibility for their child's asthma and children relinquished their developing autonomy.

## **5.7 Summary**

The findings identified that increasing independence was influenced by the child's developmental stage and opportunities to engage in decisions. Children reported waiting for assistance if their asthma symptoms presented when younger, but as the child develops they demonstrate self-management behaviour within the decision-making process and this enables some to take more responsibility for asthma management. Across the age ranges the children typically requested support from their parents which was highlighted as a key part of managing their asthma. This support included relying on parents to recognise changing in breathing and relying on prompts from parents to take medication. Support from parents was viewed as a means of sharing decisions about asthma management which ameliorated concerns about making wrong decisions.

Uncertainty in relation to parents handing over the responsibility to their children for their asthma management resulted in roles and responsibilities for asthma management being a dynamic shifting process. The tension and sometimes dilemmas between parent dominated decisions versus facilitating the child's responsibility for decisions emerged as a dominant feature of both children's and parents' accounts of managing childhood asthma. Parent confidence in the child's autonomous management of the asthma increased when there were a reduced number of asthma exacerbations, when the child was taking their preventative inhalers; or when there was a reduction in night time symptoms, indicating the asthma is being managed appropriately. Child and parent comments illustrated the beginning of a shared approach to managing the child's asthma, albeit the ultimate decision-making process remains with the parent. Children alert their parent when they require assistance with asthma management decisions.

Children and parents express a range of preference decisions, demonstrating how a child begins to take responsibility for asthma management decisions but still retain parent's

support with some decisions. A child may find it difficult to breathe and may associate that with needing their inhaler, across ages and make various decisions, asking their parent for support or just getting on with it and administering the inhaler independently. The important role of parents in supporting and allowing the fluctuation of asthma management control from parent to child encourages the child to make an informed decision regarding their care management. A parent would allow the child control of the treatment decision but prompt the child if they appear to be ignoring their asthma symptoms. Although the participants recruited for the study attended an asthma review clinic, parent comments highlighted they were not always compliant with the health care professional's advice.

The findings indicate that decision-making is a shifting and shared process from parent dominated decisions to child control over the management of their asthma and vice versa. Several factors impact on the direction of the decision. Children do not always want autonomy for all decisions relating to their asthma management and may seek advice from their parent or they may want their parent to dominate the decision. Parents operate at different levels to support their child and maximise their child's health, for example, assuming responsibility for the decisions if they perceive the symptoms to be severe.

Contextual factors and individual preferences appear to dominate the direction of the decision; if a parent, especially the mother is present, the child may relinquish control of the decision and allow their mother control of the decision. The child's experience of managing their asthma and cognitive development is an important factor in the level of participation the child exhibits, although decision-making responsibility for asthma management tasks is not age-bound. Children make decisions but in this age group want to share the responsibility of the decision outcome with parents. The length of duration since diagnosis also does not appear to relate to the level of decision-making responsibility. The findings from the data suggest participating within the decision-making process from a young age will increase the child's confidence that they are able to manage their condition, resulting in the increased likeliness of positive health behaviour management of their asthma condition throughout adolescence and adulthood.

For both children and parents the accessibility of the inhaler was identified as important as both an enabler and hindrance for the child's self-management of asthma. The start of self-

management involved the child making autonomous decisions in relation to requiring their inhaler in response to their asthma symptoms. If the child is at home and the inhaler is accessible they are able to respond quickly and make the decision to undertake the treatment required to alleviate their asthma symptoms. If the child is at school, they must have consent from the school staff to access their inhaler, consequently delaying treatment and impacting on the child's ability to operate autonomously. This issue could be taken forward with the School Nurse and like Nathaniel best practice for children having free access to their own inhalers identified.

Across the age range parent's accounts suggest they develop confidence in their child's ability to self-manage their asthma management decisions, as their child gains experience and begins to make decision that are in concordance with expected management plans for example, administering their own inhalers in response to recognising specific triggers and asthma symptoms. Collaborative communication between the child and parent, with the parent exploring the needs of the child, who maybe wants or does not want more autonomy relating to their asthma, needs to be encouraged. However, often the presence of the mother (main carer) negatively influences the control of the decision-making for asthma management. The child and parent comments may suggest confidence in their own/child's ability to make autonomous decisions for the management of their asthma, yet in reality within the home environment, the mother is still involved. This may not be detrimental to the development of autonomy as children identified positively with this reassuring support and help, allowing the shifting of asthma management responsibility.

The children's accounts suggest they perceive that they have limited control of their asthma management decisions with the level of child autonomy being context dependent. A range of contextual factors impacted on child and parent decision-making such as preferences, relationships, severity of illness symptoms, additional illness and whether the main care-giver is present. How the family operates and makes decisions within the home environment influences the child's participation within the asthma management, child parent relationships are explored in more detail in the next chapter.

**Chapter 6:****Independent, shifting and shared decisions**

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**6. Introduction**

In the previous findings Chapter 5 decisions were described that were made independently by the child and their parent, but there were distinct contextual factors and influences that ‘thickened’ (increased) or ‘thinned’ (reduced) a child’s agency in making decisions (Klocker, 2007:p85). This chapter explores situations when more than one contextual influence is present to gather a deeper understanding of how decisions are made independently, with control shifting from child to parent or decisions shared between both. In-depth analysis of asthma management decisions within family dyads exposed decision maps from child and parent comments that clarified where certain decisions were positioned along a control continuum and the shifting of decision control and decision dilemmas within different contexts and family characteristics.

Seven contrasting contextual situations are explored, these include:

- Parenting style influences child agency and self-confidence
- Cognitive development, decision-making and child agency
- Shared decision-making used to build self-confidence and develop child agency
- Parent absence increased autonomy and child agency
- Shifting decisions and parenting style with severity of illness
- Undermining confidence and child’s ability to make decisions reduces autonomy
- Accessibility of inhaler and reduced autonomy

Each theme will be explored using one family as an example case or comparing and contrasting families against one another to demonstrate the interplay of influencing factors.

## 6.1 Parenting style influences child agency and self-confidence

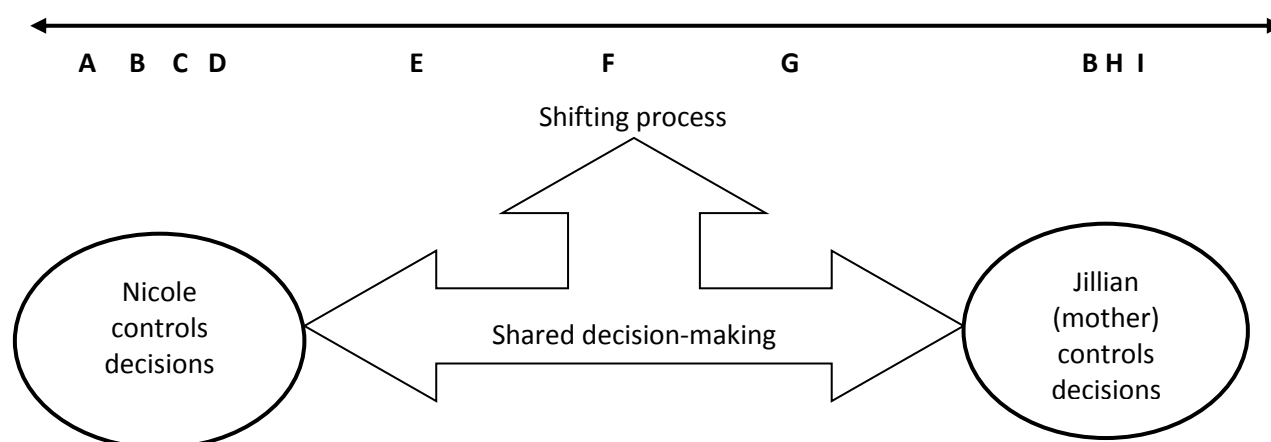
Three parenting styles were identified within the family dyads: permissive, authoritative and authoritarian, with none of the parents in the families recruited demonstrated an 'uninvolved' parenting style. This theme brings together three different examples where family decisions regarding asthma management were directly influenced by the parenting style of their closest parent, in all cases the mother even when both parents were interviewed. The parenting style appeared to influence the child agency, their ability to make independent decisions and self-confidence in managing their own asthma.

### 6.1.1 *Permissive parenting style increases child agency and independence*

*Nicole 11 and Jillian (mother)*

Nicole eleven years of age lives with her mother, father and older sister. Jillian, her mother works part time as a company director. Nicole is aware that her brown inhaler needs to be administered morning and night. The blue inhaler is administered twenty minutes before exercise, following mother researching additional measures to facilitate Nicole's participation within sport. Nicole enjoys riding her bike. She demonstrates agency in the management decisions of her asthma. If she has symptoms during the night she will administer the blue inhaler herself and only wake her mother if the symptoms persist. Nicole ignores her father's request to administer the brown inhaler, as she says nothing happens if she doesn't take it. Nicole *'pushes herself to keep up with her friends'*. Jillian, Nicole's mother demonstrates a permissive parenting style. The findings identify that Jillian typically allows Nicole to make the decision however, if Nicole and her mother disagree on an asthma management decision, Jillian will tell Nicole to administer the inhaler if she thinks it is required. Figure 4 presents the family decision map as a continuum of examples of *what* decisions are made, *when* and *who* has control of the decision.



**Figure 4: Nicole 11 and Jillian (mother) decision map**

Key	Type of decision
A	Decides whether cough and wheeze is a symptom related to asthma
B	Decides to administer treatment
C	Decision to minimise risk of specific trigger
D	Decides on mode of administration
E	Decides to involve and ask mother advice when present
F	Decision to allow mother to observe inhaler use when present
G	Mother decides to prompt inhaler use
H	Mother decides treatment in presence of additional illness
I	Mother decides treatment and action when symptoms persist following inhaler use

The example comments demonstrate the decisions where Nicole has control; Jillian, her mother has control; and where the decisions are shared. The family decision map illustrates Nicole's high level of agency within the asthma management decisions, demonstrating control over administering the treatment in the presence of asthma symptoms, avoiding or modifying behavior with triggers and when to resume leisure activity following an acute asthma episode. Jillian, Nicole's mother demonstrates a permissive parenting style, typically allowing Nicole to make autonomous decisions.

*'I kept coughing and started wheezing so I take my inhaler. I needed it once and then I was kind of ok after a few minutes. I take my blue one twenty minutes before exercise and the brown inhaler is in the mornings and night'* Nicole 11

*'I stayed in school until I felt better then I went back outside. That was my decision not my teacher's that I could go back out and play'* Nicole 11

*'When I do running I usually take this (inhaler) and I take it twenty minutes before exercise cos it opens the 'breath ways'. We (friends) were playing 'tig' and I was getting out of breath but I wanted to keep up with my friends'* Nicole 11

*'My mum thinks I should take it (inhaler) with a spacer...I shouldn't but I usually take my inhaler without the spacer'* Nicole 11.

*Sometimes my mum will say 'oh, I don't know' and I would say 'well I think I need it (inhaler) so my mum will say 'oh, ok if you think you need it'* Nicole 11

*'She knows how she feels better than anyone. She is responsible for taking her reliever and preventer inhalers'* Jillian, mother of Nicole 11

The following extracts demonstrate the shifting process of decision influence. Nicole frequently makes autonomous decisions but requires assistance from her mother in different contexts. For example, in the presence of additional illness, if symptoms persist following self-administration of the inhaler, as demonstrated within the following extracts:

*'She would usually bring the 'rasp' to me and if she disagreed with me I would advise her to have it (reliever)'* Jillian, mother of Nicole 11

*'If my asthma was really bad and I had a cold I would go and wake my mum up cos she might give me some calpol as well'* Nicole 11

*'If it 'asthma' was really bad and I had taken my inhaler then I would go and wake my mum up'* Nicole 11

Nicole requests support and reassurance from her mother for some management decisions, particularly if symptoms are severe (discussed in later theme). The permissive parenting style influences and promotes self-management, 'thickening' Nicole's agency, through helping her to problem solve and make decisions with support.

*'Sometimes when I have a bad cough and I am a bit shaky I will ask my mum if I should take my inhaler. She will say if you are wheezing or your chest is tight then that is up to you and she kind of helps me to make that decision'* Nicole 11

*'The good thing about sharing decisions is if you think no and your parents think no, then definitely no'* Nicole 11

*'Sometimes I ask my mum because I don't know whether I should or shouldn't (take inhaler)'* Nicole 11

*'Sometimes I ask my mum if she is right next to me cos I wouldn't like to take it without telling her'* Nicole 11

Nicole demonstrates agency within the asthma management decisions and autonomy with treatment decisions, specific trigger avoidance and mode of inhaler administration. Nicole disagrees with her mother on some decisions, for example the use of spacer to administer the inhaler or not taking the reliever inhaler when her mother requests. However, she does seek support from her mother (when she is present) to share the decision to take her inhaler. Indeed she has already made the decision to take the inhaler but she seeks her mother's involvement, confirmation that the decision is correct. In the presence of additional illness or ineffective inhaler use, Nicole does however 'shift' the control of the decision back into her mother's responsibility.

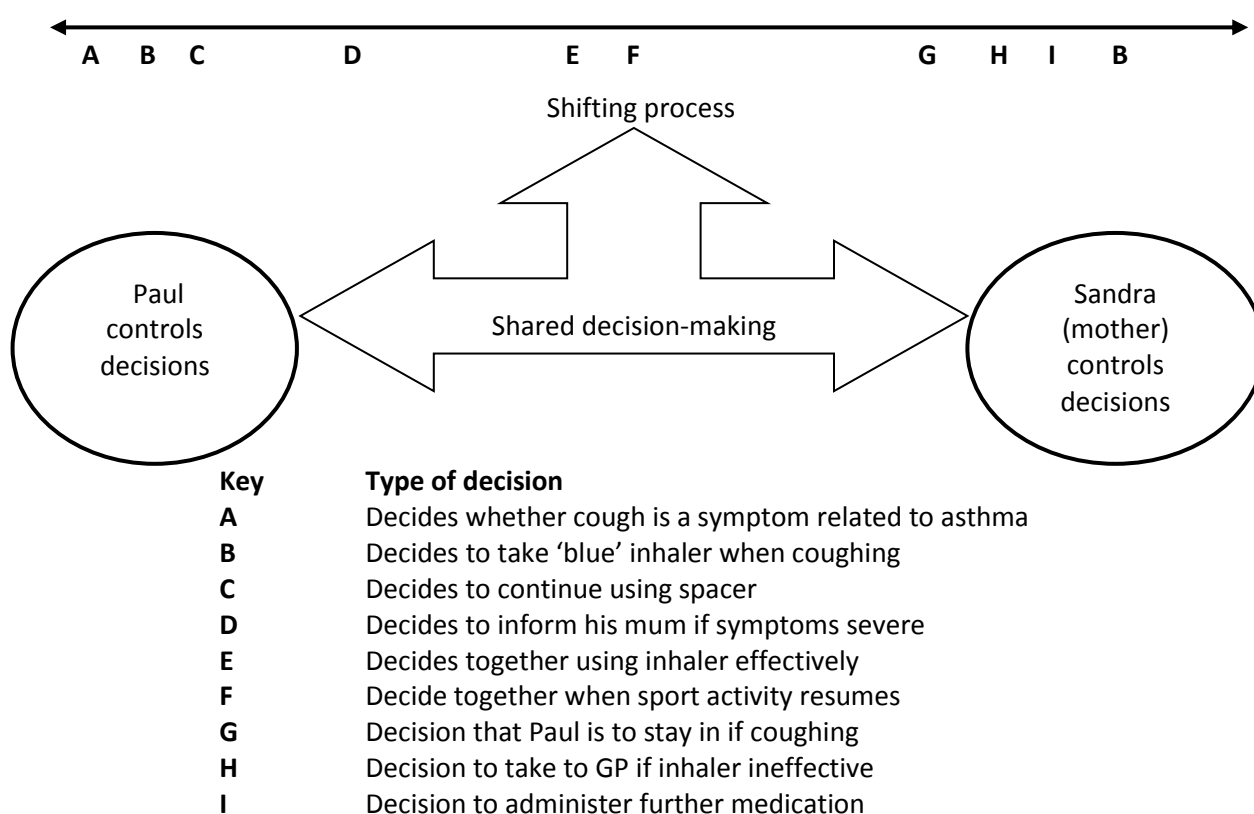
### **6.1.2 Authoritative parenting style encourages child agency and shifting decisions**

*Paul 8 and Sandra (Mother)*

Paul, aged 8 years was diagnosed with asthma at 18 months of age. He lives with his mother, father and brother. Mother works full time as a health care professional and his father remains at home. Paul enjoys playing football and his family, friends and school teachers help with asthma management decisions. He carries his own inhalers when playing out with his friends. He knows what, when and how to administer the asthma treatment. He understands the purpose of the reliever inhaler but only acknowledges the preventer inhaler by colour. He does not describe the purpose of the 'brown inhaler' and his mother acknowledges he does not understand the reasoning behind the preventer inhaler. Paul's

mother encourages self-management but sometimes has to prompt inhaler use. An Authoritative parenting style is observed within this family unit. Figure 5 presents a family decision map demonstrating examples of *what* decisions were made and *who* has control of the decision, as a continuum.

**Figure 5: Paul 8 and Sandra (mother) decision map**



Paul has control when asthma symptoms present and treatment is required. He also makes the decision how to administer the inhaler medication despite the health care professional saying he is too old to use his 'mask'. His mother reports she has confidence in her son's ability to be the main decision-maker.

*'I know when I need it, a blue one (inhaler). I know to take it when I start coughing'*

Paul 8

*'I stop playing football because of my asthma'* Paul 8.

*'He is just one of those children that takes it (asthma) all in his stride. He copes with it all. He takes the responsibility as part and parcel of who he is'* Sandra, mother of Paul 8

*'The doctor said he is too big for his mask and he will have to change it to a spacer. He isn't too big and he isn't conscious of it in school. I am guided by what Paul wants to do'* Sandra, mother of Paul 8

*'His dad was worried about him doing football but I just think he has to live normally'* Sandra, mother of Paul 8

*'He has his inhaler and spacer under his pillow'* Sandra, mother of Paul 8

*'It is normal to him he has his inhaler morning and night...that is part of his routine'* Sandra, mother of Paul 8

Sandra takes control over decision-making when symptoms are more severe or when Paul 'shifts' the control of the decision-making back to his mother. This includes whether he should take his inhaler (see figure 4 decision B at both ends of the continuum) or requires further intervention and during sport if asthma symptoms develop.

*'I give it (inhaler) to my mum and when I come off the pitch she gives it to me'* Paul 8

*'If I am coughing my mum says I have to have my inhaler and I have to stay in'* Paul 8

*'Depending if his inhaler had any effect I would give him his prednisolone or take him to the GP'* Sandra, mother of Paul 8

Shared decisions for asthma management occurred when support and reassurance was required by Paul, for example when he needs reassurance that he is administering the inhaler correctly. However this sharing of decision has a reciprocal benefit because it provided Paul's mother with reassurance that Paul has the ability to take the necessary decision actions if the medication is ineffective in reducing the asthma symptoms.

*'Me and my mum decide when I can go back on the pitch'* Paul 8

*'My mum checks but I know how to do it (administer inhaler) myself'* Paul 8

*'Well when he has woke me up to say he needs his inhaler I will probably sit with him for a while to see if it is a little bit more and do we need to go to the hospital'*

Sandra, mother of Paul 8

Paul's mother encouraged self-management through shared and supported decision-making but at the same time demonstrated an authoritative parenting style typology. She allowed Paul to demonstrate agency, illustrated by the 'map', but his mother had control over the decision in the presence of nocturnal asthma symptoms, if the inhaler is ineffective and when/if to seek healthcare advice and when to resume physical activity following specific asthma symptoms. The decisions were shared when asthma symptoms were mild, when checking effective inhaler use, during physical activity and when to resume sport after experiencing asthma symptoms.

### **6.1.3 Authoritarian parenting style reduces child agency and autonomy**

#### *Amanda 9 and Kirsty (mother)*

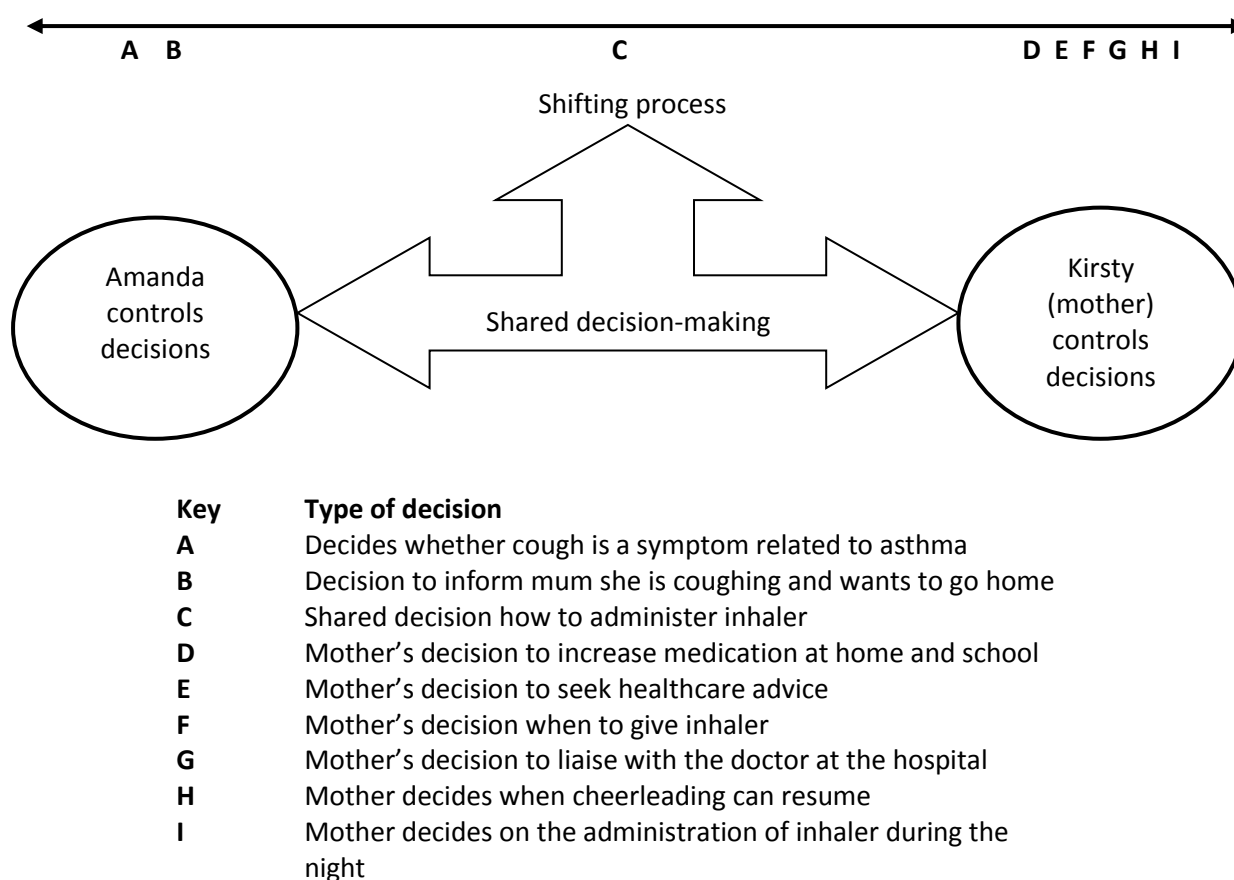
Amanda nine years of age lives with her mother, older brother and younger sister. Kirsty, Amanda's mother is a stay-at-home mum. Amanda was diagnosed with asthma at four years of age, she also has eczema. She enjoys participating in physical activity and is able to associate her coughing as a symptom of her asthma. Amanda claims she does not want to make any asthma management decisions and that her mother always takes control. Kirsty demonstrates an authoritarian parenting style where Amanda complies with her mother's asthma management decisions. Amanda demonstrated limited agency. The child extracts imply Amanda does not want to make any decisions and she admits she does not want any control but this could be attributed to her mother's authoritarian parenting style reducing her locus of control. Figure 6 presents the family decision map and examples of *what* decisions are made and *who* has control of the decision.

Amanda demonstrates little control over the asthma management decisions. She is aware of the asthma symptoms and when treatment is required to alleviate the symptoms but does not administer the medication herself.

*'I know my asthma is starting up by coughing and I struggle to breathe'* Amanda 9

*'At the park I started running around and coughing. I told my mum that we needed to go home'* Amanda 9

*'She knows herself when she is not feeling well'* Kirsty, mother of Amanda 9

**Figure 6: Amanda 9 and Kirsty (mother) decision map**

Kirsty, Amanda's mother has control over the asthma management decisions and Amanda's agency is 'thinned'. This is demonstrated by Amanda's mother holding the asthma medication in a locked cabinet and reducing Amanda's locus of control, further reduced by the need to sleep in the same room as her mother, so she can keep a close watch on her and be available if needed.

*'Mum makes all the decisions about my asthma. I don't want to be involved in any decisions'* Amanda 9

*'I have my inhalers at night and it is my mum that remembers'* Amanda 9

*'Mum talks to the nurse or the doctor at the hospital'* Amanda 9

*'When I was out of breath at cheerleading, after I had had my puffers my mum decides that I can go back cheerleading'* Amanda 9

*'When she first started school I thought this is going to be a problem because I am not going to settle whilst she is at school'* Kirsty, mother to Amanda 9

*'When she started school I was concerned as I wasn't going to be there to help her'* Kirsty, mother of Amanda 9

*'Her medicines are in a cupboard that nobody can get into'* Kirsty, mother to Amanda 9

*'Every morning we get up and breakfast, brush teeth and we take the inhaler'* Kirsty, mother to Amanda 9

*'She sleeps in the same room then we can get some sleep'* Kirsty, mother to Amanda 9

The parenting style reduced Amanda's agency. When Amanda started school, her mother expressed concerns over the handing over of the asthma management decisions to the school staff and was uncomfortable with the loss of control over her daughter's asthma management. Amanda clearly states she does not want control over management decisions but it may be she lacks confidence due to her restricted participation within the decision-making process. There are some decisions that Amanda shared with her mother, such as when she wants and needs her inhaler and her mother agreed. Amanda demonstrated a lack of confidence in the administration of treatment and there appeared missed opportunities to teach Amanda how to administer the inhaler herself, rather than just doing it for her.

*'If I was at home then I would tell my mum I need my 'puffer' and she would go and get it and do it for me'* Amanda 9

*'She normally holds the spacer and I put the inhaler there then she uses it with me watching'* Kirsty, mother of Amanda 9

Amanda's mother controls the asthma management decisions and demonstrates an authoritarian parenting style, the child complies with her mother's decisions and as the 'map' demonstrates, limited agency is demonstrated by Amanda. Although Amanda reports she does not want any control over the decision-making, she does recognise coughing and struggling to breathe is related to her asthma. She is also aware treatment is required and informs her mother, who then obtains the asthma medication from a locked drawer and



administers the inhaler to Amanda. It was not clear whether Kirsty considered Amanda too young to make decisions or not sufficiently developed to be able to develop the autonomy for her asthma management. It would be interesting to observe this family dyad over time to see when and why decision control shifts more towards Amanda. Kirsty is a single parent and a stay-at-home mother which may expound an over protecting role, however there was a comment she made when discussing severe symptoms *'I don't want to go back to the situation where she is in hospital'* which suggested she may have had a bad experience which was influencing her authoritarian style of parenting. This is something a health care professional needs to be aware of and potentially offer a debrief discussion to parents and children following hospitalisation for severe asthma symptoms. It was evident that this fear of getting worse may prevent the shifting and even the sharing of decisions and the child's development into an independent decision-maker.

## **6.2 Cognitive development, decision-making and child agency**

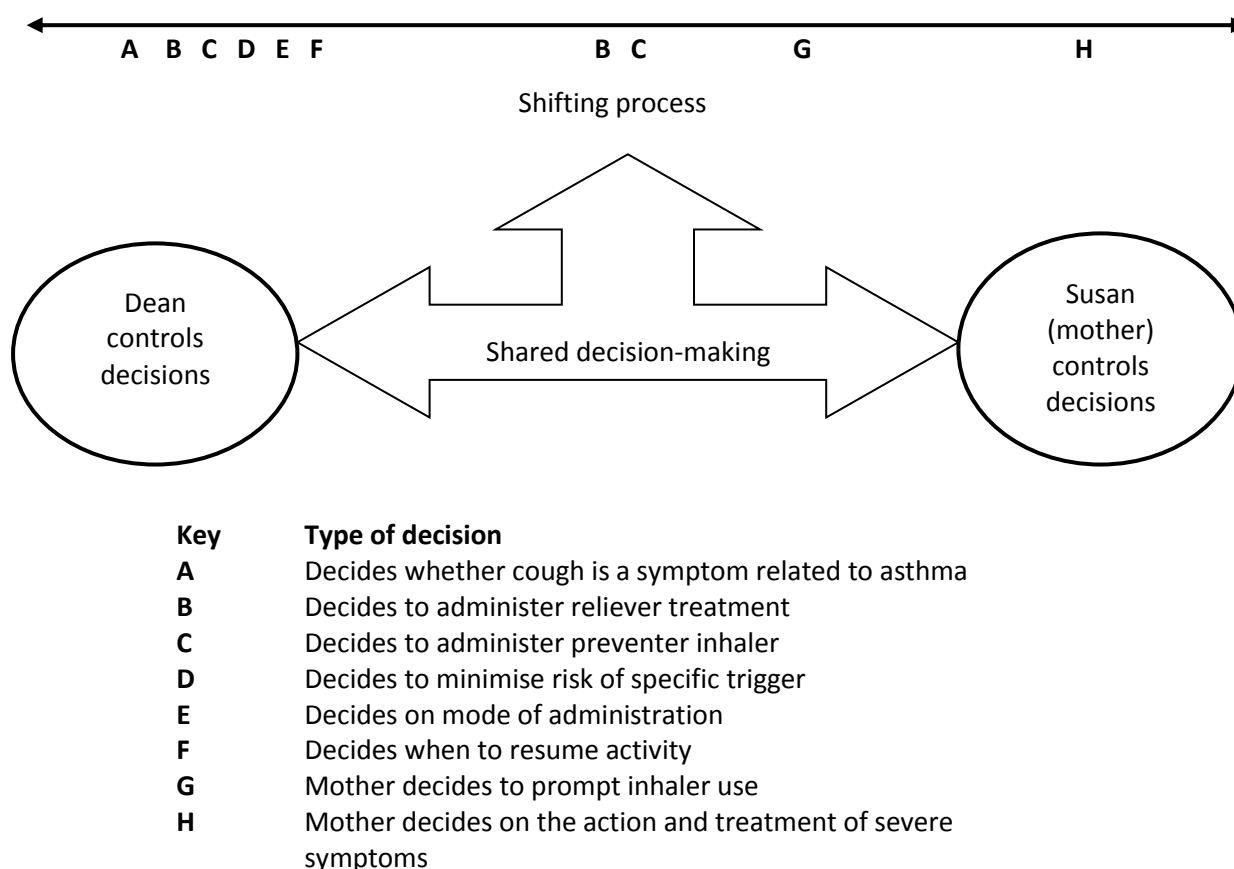
Cognitive development stages of a child's thinking and reasoning ability become more complex as a child increases in age, but it is important to note that each child will develop at different rates and age is not always an indicator of their ability to make independent decisions regarding the management of their asthma. This theme presents Dean one of the youngest participants who demonstrated a high level of autonomy organisational skills and increased agency compared to other children who were older (such as Amanda above).

### *Dean 7 and Susan (Mother)*

Dean seven years of age lives with his mother, step-father and brother. His mother works part time. Dean enjoys playing out with his friends. He has a dog, a variety of fish and reptiles. He also has a diagnosis of eczema. Dean demonstrates agency in the management decisions of his asthma. He will administer the reliever and preventative inhaler. He is able to acknowledge asthma symptoms that require treatment and in the presence of symptoms he will restrict physical activity. Susan, Dean's mother demonstrates a mostly permissive and only occasionally authoritarian parenting style, as she typically allows Dean the control over the majority of management decisions but dominates decisions in the presence of more

severe symptoms. His organisational skills facilitate his mother's confidence in his ability to manage. The only decision that Dean 'shifts' the control back to his mother is when he experiences severe symptoms from additional illness when he gains reassurance from her support. She takes control of the decision if further health care advice is required, when the symptoms continue to deteriorate. Figure 7 presents the family decision map as a continuum of examples of *what* decisions are made, *when* and *who* has control of the decision.

**Figure 7: Dean 7 and Susan (mother) decision map**



The family decision map illustrates the high level of agency that Dean demonstrates within the asthma management decisions with a concentrated number of decisions controlled by Dean. He recognises his cough symptoms relate to asthma, the administration of reliever and preventative inhalers, reducing his risk of specific triggers and when to resume leisure activity following an acute asthma episode.

*'I have my preventer in my room, which is the one I take each morning and night'*

Dean 7

*'Pets don't make my asthma worse and cold weather doesn't either. My asthma starts up when I am doing sports then I know to go and get my inhaler'* Dean 7

*'I use the one in my room. If I am coughing really bad I might just take two puffs'*

Dean 7

*'I still enjoy running around I would carry on doing it but not as fast'* Dean 7

*'I would make that decision myself to use my inhaler at school but my mum might help at home'* Dean 7

*'He listens to his own body, he knows how he is feeling and doesn't know it any other way. You have to teach these children what their limitations are. As he gets older I am with him less and less...another life skill he has to manage because of the condition he has)'* Susan, mother of Dean 7

*'He will always say I am having it (inhaler) and he will just go and get it. If his asthma does start he will have his inhaler. He doesn't avoid anything that may trigger his asthma'* Susan, mother of Dean 7

*'He takes his medication straight through the inhaler although we get conflicting advice'* Susan, mother of Dean 7

Susan, Dean's mother generally allows Dean to self-manage his asthma but was strong in her view, showing an authoritarian parenting style that as soon as his symptoms become worse she will dominate the decision-making and take back the responsibility from Dean regardless of his decision preferences.

*'We would involve Dean unless we thought this was something more. It would be my decision if we were going to the hospital. It is my decision if he has time off school due to his asthma. Obviously if it is a really bad attack I would take over regardless of what he wanted'* Susan, mother of Dean 7

*'I only let my mum know if it is really bad.'* Dean 7

*'When I had whooping cough and I wanted to play out, I asked my mum if I could play out.'* Dean 7

When discussing this with Dean he was very happy to share the decision-making with his mother and it didn't impact on his autonomy, agency or self-confidence. He indicated how he appreciated his mother prompting him as he knew himself sometimes he forgot to take his inhalers and she was also better at spotting him starting to wheeze.

*'Can't feel myself wheezing but mum might see me like puffing she will say do you want your inhaler and I will say yes'* Dean 7

*'I like sharing decisions with mum otherwise I might forget to take it (inhaler).'* Dean 7

*'Maybe I have said do you need it (inhaler) and he will say no. I will just leave it and monitor him and nothing happens'* Susan, mother of Dean 7

Dean is encouraged to be autonomous to make sure when he is not with his parents he can make appropriate decisions regarding his asthma management. So the control of decisions, for the majority of the time, rest with him, he demonstrates higher cognitive development and child agency but either allows the control to fluctuate or relinquishes control when his mother chooses to take over, only in presence of severe illness.

*'He sleeps at my parent's house and we just pack everything for him and he would just sort it out'* Susan, mother of Dean 7

Dean demonstrates agency with the majority of his asthma management decisions and is highly organised which contributes to his mother's confidence in his ability to self-manage effectively. Cognitive developmental psychology provides valuable information about a child's cognitive abilities, which can be applied to understand the child's level of participation within the shared decision-making for their asthma management. Earlier in the thesis Piaget's cognitive developmental stages indicated that a child's thinking and reasoning ability become more complex as their chronological age increases. Within this study the youngest child is one of the most confident and independent children with respect to the self-management of his asthma (comparable to Nathaniel who was 11) and other older children within the study. This highlights that the rate of cognitive development for each child is very different and may be influenced more by society and contextual influences. In the case of Dean his learnt organisational skills which enhance his ability to manage effectively, alongside the permissive parenting style and his parent's reinforced confidence

in his ability facilitated his increased self-efficacy. What was important to note was that sharing decisions did not hinder autonomy or child agency but provided reassurance and support.

### **6.3 Shared decisions used to build self-confidence and develop child agency**

This theme demonstrates how an authoritative parent style which fosters and promotes shared decision-making between the child and the parent begins to encourage self-management with support and reassurance of sharing the responsibility for the decisions made.

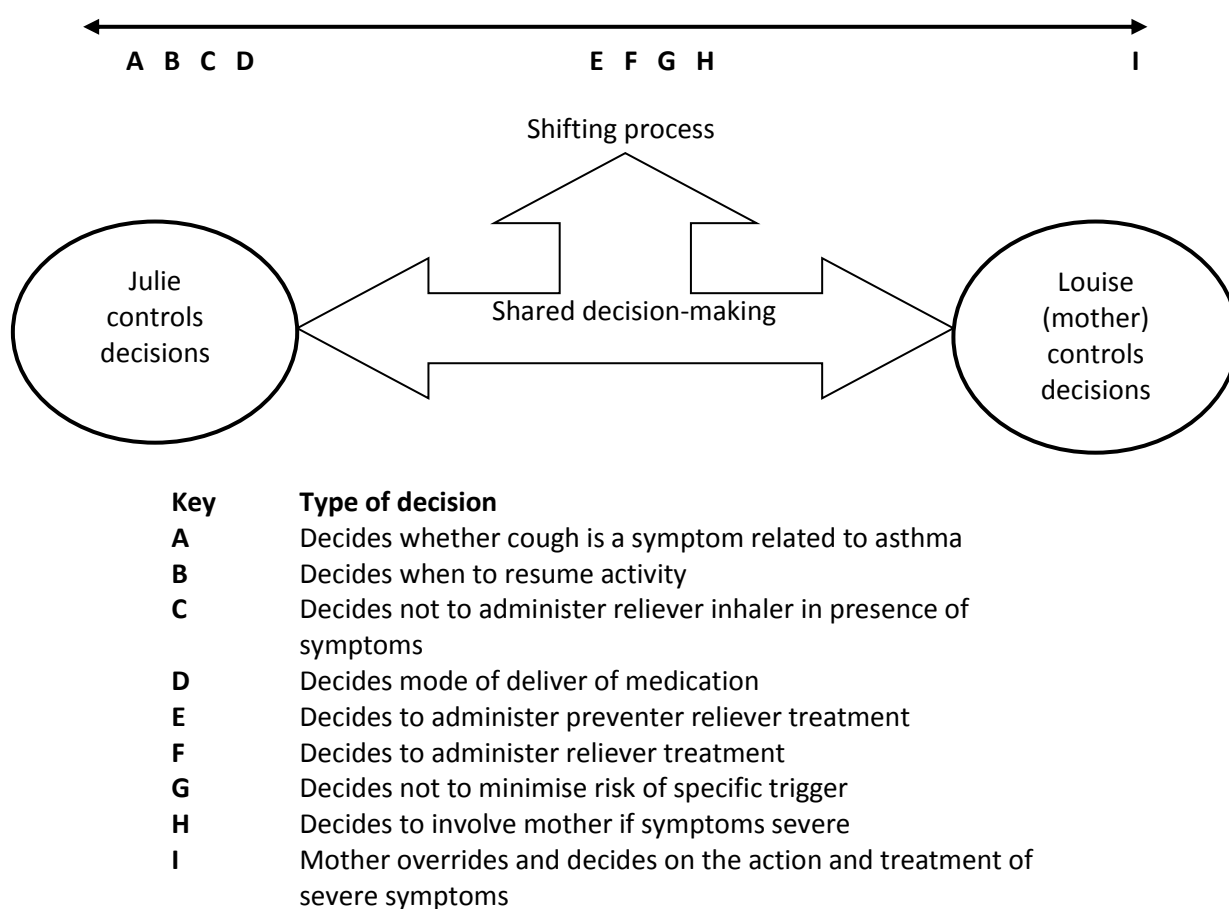
#### *Julie 8 and Louise (mother)*

Julie, eight years of age, lives with her mother and sister. Mother is employed part-time as a health care professional. Julie has been diagnosed with eczema too. Julie enjoys playing out with her friends and going for walks with her mother and sister. Julie makes the decision when to take her blue inhaler which is kept in a drawer at school and in her mother's drawers at home. Julie decides to administer the inhaler via a volumatic at home and an aerospacer at school. A plastic or metal device used to help deliver the inhaler to the child's airway and does not reduce the efficacy of the inhaled medication (SIGN, 2011). It is her mother that decides how many 'puffs' of inhaled medication she has to take, although Julie does make the decision to alert her mother when she is experiencing asthma symptoms. Julie usually makes the decision to take her reliever inhaler but admits she sometimes forgets to take her preventative inhaler. Julie reports to making the decision independently to administer her 'blue' inhaler if her mother is absent. Julie's mother demonstrates an authoritative parenting style as Julie is allowed some agency but her mother still dominates the asthma management decisions. Figure 8 presents the family decision map as a continuum of child and parent extracts and examples of *what* decisions are made, *when* and *who* has control of the decision.

The family decision map illustrates the agency that Julie demonstrates over some of the asthma management decisions. The examples provided within the key identifies Julie

demonstrates agency when deciding cough and chesty symptoms require treatment, the decision when to resume activity following the onset of asthma symptoms, decides not to administer reliever inhaler in presence of symptoms.

**Figure 8: Julie 8 and Louise (mother) decision map**



Louise, Julie's mother demonstrates an authoritative parenting style as she generally allows Julie agency with the decisions only dominating the decision if asthma symptoms are severe or covertly contacting the school staff to inform them to administer the inhalers. The following child and parent extracts demonstrate Julie's developing and 'thickening' agency.

*'I start coughing and so I have my blue inhaler. I take my blue one when I am chesty and my brown one is for everyday use. The wind starts me coughing and sometimes running starts me coughing too'* Julie 8

*'If it is really windy when I am cycling sometimes I will lose my breath. I won't always take my inhaler though'* Julie 8

*'There are times when I think I need my blue inhaler and my mum doesn't but I will just take my inhaler anyway'* Julie 8

*'I know I am taking my puffers right because my mummy showed me how to do it. I take my inhalers by myself at my dad's house'* Julie 8

*'If I was playing in my bedroom and started coughing I would come down and tell my mum but by myself I might have my puffer'* Julie 8

*'She always starts with a runny nose and a cough. She then gets a feeling in her throat, she has said that a few times. You have to make them aware of what to do...she needs to be able to 'voice' a problem'* Louise, mother of Julie 8

*'She will always make her own decisions at her father's and at school but I think she knows that I will help her at home'* Louise, mother of Julie 8

Julie has agency with some decisions such as administering the medication but shifts the decision back to her mother when she experiences severe symptoms. The following child and parent extracts demonstrate how Louise takes control of the management decisions.

*'Sometimes if I think I need two more puffs I will go and ask my mum if I should. Mum tells me how many puffs I am having'* Louise, mother of Julie 8

*'She is a bright little girl but she is also a stubborn girl. If I think she needs her reliever inhaler at school but she doesn't then I will ring up school and tell them to give it to her'* Louise, mother of Julie 8

Julie and her mother share the control of many decisions and rarely disagree over asthma management.

*'There is never a time when I think I need my inhaler and my mum doesn't'* Julie 8

*'If it is windy and I am going out with my mum, we will make the decision together whether to go the short or the long way. I like making decisions with my mum cos I love her. It also helps me to make a decision when I am at school'* Julie 8

*'I press it and my mummy watches me press it. I would go into my mum's bedroom and get it (inhaler) then tell my mum I had had my inhaler'* Julie 8

*'If I am coughing I would come downstairs and tell my mum and she would sit me down and bring my medicines out and give me my inhaler'* Julie 8

*'I give her a few choices and she makes the decision, we have done that since she was little'* Louise, mother of Julie 8

This family example indicates how a child's agency can be encouraged and developed using shared decision-making to provide reassurance and support. Contention does not arise within this family as Julie asks her mother for support and guidance in managing her decisions and enjoys shared decision-making. Julie's mother dominates decisions when asthma symptoms are severe or when Julie requires guidance or symptoms have been present. Julie's mother knows her daughter does not like to take the inhaler at school, as she does not like *'to be singled out'*, so to prevent conflict with her daughter she makes direct contact with the school to request they administer the inhaler. Julie admits to liking sharing decisions with her mother, therefore how the mother manages the control of the decisions when the symptoms are severe, is effective.

#### **6.4 Parent absence increased autonomy and child agency**

It was interesting within a number of interviews to note that a child's agency and autonomy increased when their primary parent (usually their mother) was absent. Even when their father was present children often preferred to make independent decisions and in some cases go against the advice of other parents believing they knew best. A good example to demonstrate the influence of the absent parent on child agency is through Alicia and her mother Lynn.

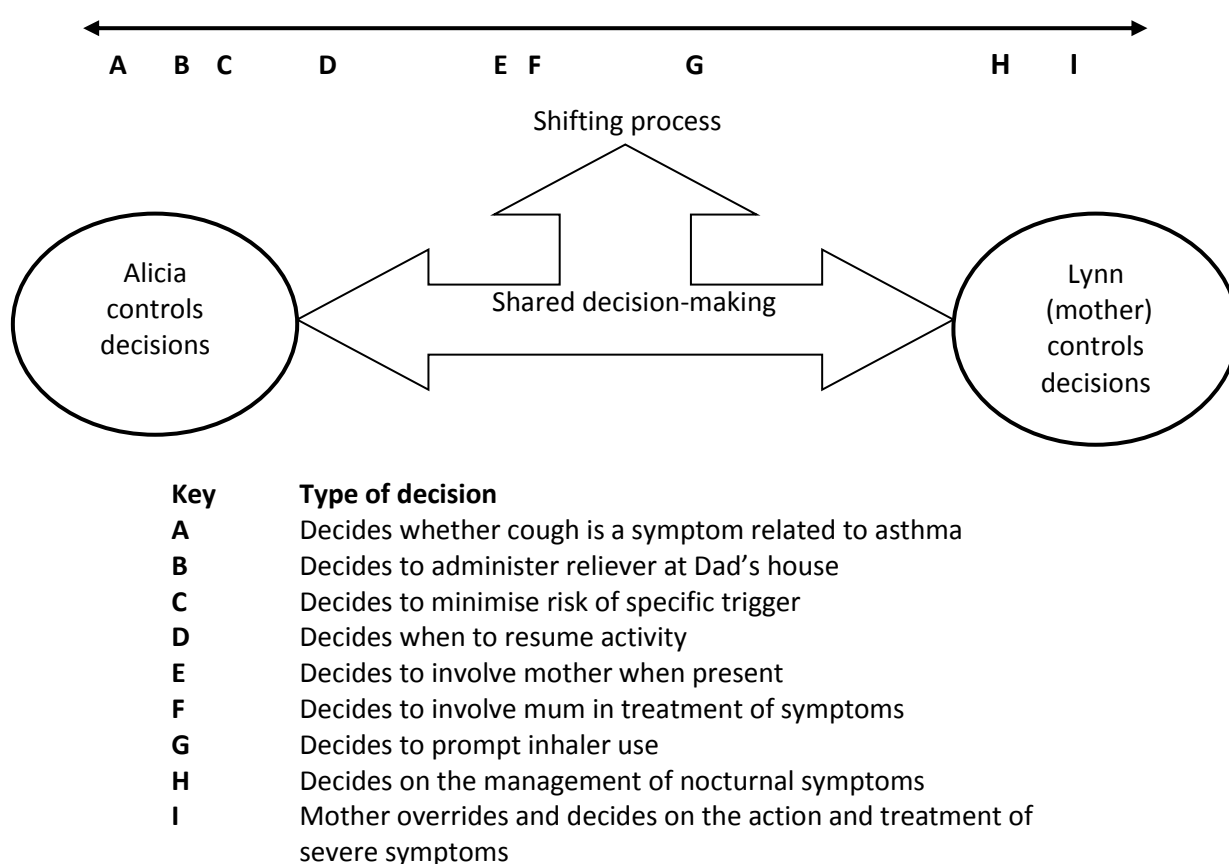
*Alicia 10 and Lynn (mother)*

Alicia ten years of age lives with her mother and younger brother. Her father does not live with the family. Her mother works part time. Alicia enjoys playing out with her friends and enjoys dancing and running. She sometimes requires her reliever inhaler during dancing.



Alicia demonstrates some degree of agency in her decisions surrounding asthma management. If she has symptoms during the night she will wake her mother who will administer the blue inhaler herself. She reports that her father will offer her the reliever inhaler in the presence of a cough. Alicia sometimes demonstrates agency when to resume activity following an acute asthma episode. Lynn, Alicia's mother demonstrates an authoritative parenting style. The findings identify that Alicia demonstrates agency over some management decisions but her mother's decision preference dominates. Figure 8 presents the family decision map as a continuum of examples of *what* decisions are made, *when* and *who* has control of the decision.

**Figure 9: Alicia 10 and Lynn (mother) decision map**



The family decision map illustrates the agency that Alicia demonstrates within the asthma management decisions. The examples provided within the key identify that Alicia demonstrates some degree of agency over the control of administering the treatment in the presence of asthma treatment (especially when she is at her father's house) and when to resume the leisure activity following an acute asthma episode. Lynn, Alicia's mother demonstrates an authoritative parenting style as she typically allows Alicia to make some autonomous decisions. The following child and parent extracts demonstrate Alicia's agency:

*'We used to have cats and I am allergic to them...it might start my asthma off. If it (cat) goes on my bed I will ask my dad to take the cat off because I am allergic to cats. I avoid touching the cat as it might start my asthma off'* Alicia 10

*'...sometimes I will say I need it (inhaler). If I had been coughing and wheezing sometimes I might go back out and play or I might just sit and watch television. I make that decision'* Alicia 10

*'She takes her inhaler and if she needs it she has it.'* Lynn, mother of Alicia 10

*'Sometimes she will say I need it (inhaler) because I am coughing'* Lynn, mother of Alicia 10 *'She won't ask me if she can carry on dancing, she will make that decision herself'* Lynn, mother of Alicia 10

*'She has had it (asthma) a big part of her life and she is just used to it. She knows she has got it (asthma) and she knows what to do if she doesn't feel so good. She is old enough now to deal with it (symptoms)'* Lynn, mother of Alicia 10

The following extracts demonstrate the shifting process of decision influence. Alicia, frequently makes autonomous decisions but requires assistance from her mother in different contexts. For example, in the presence of nocturnal symptoms as demonstrated within the following extracts:

*'My mum helps me to care for my asthma. If I start coughing my mum will go and get my inhaler. If I start coughing during the night I would go and wake my mum and sometimes she gives me an inhaler'* Alicia 10

*'When she is with me I will probably help her more than anyone else'* Lynn, mother of Alicia 10.

*'I will say go and have your inhaler because you are coughing. I don't think she realizes she is doing it (wheezing)' Lynn, mother of Alicia 10*

Alicia requests support and guidance from her mother for some management decisions.

*'She will say if you feel like it you can go back out and play' Alicia 10*

*'If I start coughing and wheezing I will come on and ask my mum if I can have my inhaler' Alicia 10*

Alicia demonstrates some agency within the asthma management decisions. She demonstrates autonomy with acknowledging her symptoms require treatment, when to resume activities following an onset of asthma symptoms and specific trigger avoidance,. However, she does request assistance from her mother with the decision to take her inhaler during the night. Alicia 'shifts' the control of the decision back into her mother's domain. Alicia's mother demonstrates an authoritative parenting style, by generally allowing Alicia to make some autonomous decisions, usually when she is at her father's house or school but generally dominates the decision when present.

## **6.5 Shifting decisions and parenting style with severity of illness**

Throughout all the themes presented so far in this findings chapter and the different decision maps (Figures 4-9) there is consistency and consensus amongst children and parents that when symptoms are severe the autonomy for decision-making on asthma management shifts each time to the parent, irrespective of the level of child agency and child ability to make an autonomous decision at other times. This example reinforces this point through exploring the decisions between Nathaniel and his mother Jenny, Nathaniel being the most independent decision-maker of all the children interviewed.

*Nathaniel 11 and Jenny/Peter (parents)*

Nathaniel aged eleven lives with his mother, father, two brothers and a dog. His mother and father are employed as health care professionals part-time and full-time, respectively. Nathaniel enjoys physical activities such as bowling, trampolining, swimming and playing



great confidence in his own ability, indicating below he knows better than his mother what is and what isn't a symptom of asthma, how to make the right decisions and this is enhanced by his parents' confidence in him to self-manage, through their support his mother and father 'thicken' his agency to make decisions.

*'I have a brown one and a blue one (inhalers) but I can't remember their names. I get bad cough with asthma and sometimes my lungs hurt a bit and I get out of breath and to help reduce it you need blue inhaler'* Nathaniel 11

*'...cos of his dog hairs I cough a bit. I just go to sleep but sometimes I have to go away from the dog for it (itching) to settle down. I stroke the dog and wash my hands after. There isn't a lot that sets my asthma off except from dust and cold weather. I have an allergy to cats and my grandma has cats. The cats do not stop me from going to my grandma's house'* Nathaniel 11

*'I went to my friend's house and he has a hamster, I started coughing and so I decided to take my inhaler'* Nathaniel 11

*'Asthma is not that bad as long as you remember to keep taking your inhalers'*  
Nathaniel 11

*'If I start running I might start coughing and if I am running very fast I might run out of breath a bit, I would carry on running but not just as fast'* Nathaniel 11

*'Mum always thinks I am wheezing, when I go to sleep I'm not I just make funny noises. She wants me to take my inhaler but I say I don't really think I need to and I don't'* Nathaniel 11

*'I normally have an inhaler with me so I would just use it'* Nathaniel 11

*'He is very organised, not like me. He is pretty good at controlling it himself. Both my wife and I are alert to triggers of food allergies but he is even better than us. He went through a period of losing his inhalers but he seems to have got over that now. We know he can cope with his asthma himself'* Peter, father of Nathaniel 11

With similar contextual factors and characteristics to Dean (Figure 7) although four years older Nathaniel demonstrates a high level of organisational skills which certainly seem to complement the experience and knowledge developed overtime that support his decision-making. Nathaniel generally makes autonomous decisions but shares and shifts the decision

back to his mother when he experiences severe symptoms. Nathaniel's mother (Jenny) and father (Peter) demonstrated a permissive parenting style as they typically allow Nathaniel to make the asthma management decisions. There is no contention between Nathaniel and his parents they both allow Nathaniel agency over the decisions, unless the asthma symptoms are severe then the parents take control over the decision-making and Nathaniel is happy to shift responsibility to gain reassurance and support.

*'I decide to involve my mum or dad if it (asthma) is really bad...then my mum will just say to take it (reliever inhaler) if it is really bad. It (coughing) got worse so I went to my mum and she asked if I was ok. I told her that I thought I had bad asthma so she said I had to take another puff of my inhaler' Nathaniel 11*

*'If my asthma is still bad my mum says to take it (inhaler) again. I then asked my mum if we should go to the hospital and she said let's wait a bit and then she said we should go' Nathaniel 11*

*'I will say do you think you need your inhaler and he will say yes or no. Sometimes I will tell him that I think he does need it but that is rare' Jenny, mother of Nathaniel 11*

*'I am coughing really bad and my grandmother says do you need your inhaler but I will say I don't think so. If the cough carries on and my grandma says again do you need your inhaler and I say no. Then it got worse so I went to my mum' Nathaniel 11*

As highlighted earlier across the decision maps and throughout this chapter (and Chapter 5) parents control decisions regarding asthma management when symptoms are severe or if the child is experiencing an additional illness or the presence of nocturnal asthma symptoms. Nathaniel with the highest level of agency and responsibility for the majority of his asthma management also allowed the decision-making to shift and be shared with his parents, with little resistance from all children or the need for them to be making a decision when unwell. It is the recognition that symptoms are getting worse and when to ask for help that children need to be taught to ensure they seek out appropriate support at the right time.

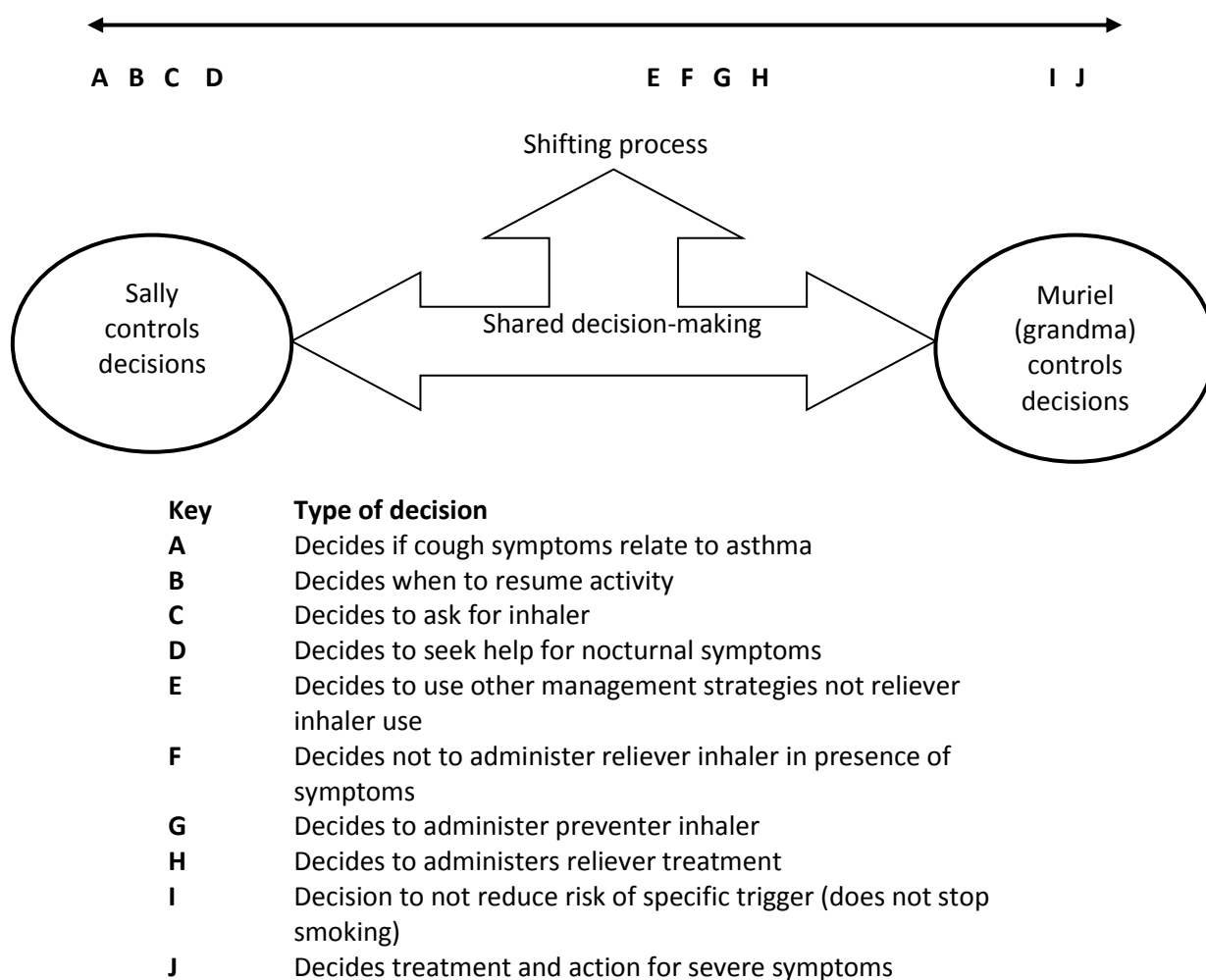
## 6.6 Undermining confidence and child's ability to make decisions reduces autonomy

The following table illustrates the parental confidence in their child's ability to self-manage their asthma management decisions.

### *Sally 11 and Muriel (grandmother)*

Sally, eleven years of age lives with her grandmother and grandfather. Her grandmother is at home full time. Sally enjoys playing out with her friends. She demonstrates a degree of agency with respect to decision-making for asthma management but this is often controlled by her grandmother. Figure 11 presents the family decision map as a continuum of examples of *what* decisions are made, *when* and *who* has control of the decision.

**Figure 11: Sally 11 and Muriel (grandmother) decision map**



Sally demonstrates agency through recognising her cough symptoms relate to asthma, when to resume activity following symptoms and the decision not to administer the reliever inhaler use during the onset of symptoms, although this decision is often not under her control. Muriel, Sally's grandmother discourages the decision to administer the reliever inhaler emphasizing the side effects and prefers her to 'rest', not recognising the immediate beneficial effects of the bronchodilator. To reinforce this control the inhalers are not accessible to Sally, she needs to ask her grandmother, who will then observe Sally administering the inhalers. The following child and grandparent extracts demonstrate Sally's limited agency.

*'I think I have had asthma since I was eight. I have been coughing all my life'* Sally 11

*'I normally take a drink of water, stop for a couple of seconds then I will carry on running. I thought of that. I don't normally take my inhaler with me because I don't need it much. I only need it if I am 'acting-up'. When we go out for a walk and my grandmother stops then I will stop for a breath as well'* Sally 11

*'She will tell me she is right and will go out to play'* Muriel, grandmother of Sally 11

*'She will take the inhalers herself when she sleeps out because she remembers to'*  
Muriel, grandmother of Sally 11

*'She is old enough, she is responsible enough'* Muriel, grandmother of Sally 11

Sally's agency for decision-making is often undermined. For example she asked her grandmother if she can go on a diet, but her grandmother refuses despite evidence that suggests the positive impact it can have on reducing incidence of asthma (SIGN, 2011). Sally does not carry her inhaler with her, despite being advised by health care professionals. She has over time been forced to develop a variety of management strategy decisions to cope with an asthma exacerbation as she is discouraged by her grandmother in using her inhaler. For example, temporarily stopping the activity and having a drink of water is effective in alleviating her asthma symptoms. Sally's grandmother demonstrates an authoritarian parenting style as she dominates the treatment decision regarding the administration of medication. If Sally thinks she may need her inhaler Muriel emphasises that asthma medication has side effects but she does not provide the information allowing Sally to make an informed treatment choice. During the interview Sally indicated on a number of occasions



rather than answering the question herself that I needed to speak with her grandmother about her inhalers as she has no knowledge of them, demonstrating reduced agency and confidence in her own ability. Whilst Muriel appeared to allow Sally some agency over the management decisions she undermined those decisions but provided no reasoning to Sally so she could understand why. Sally's lack of confidence in her own ability is evident when she states she does not like to make asthma decisions because she could make the wrong decision.

Sally occasionally makes autonomous decisions administering the medication when her grandmother is not present but the control shifts back to her grandmother when she experiences symptoms in her presence. Smoking is a specific trigger for Sally's asthma symptoms, yet she is living in such an environment, Sally has no control over the avoidance of this specific trigger, but her grandmother does. Sally alerts her grandmother when she has nocturnal symptoms. The following child and parent extracts demonstrate how Muriel 'thins' Sally's agency.

*'When I am in loads of heat...then I start coughing or because my grandma and granddad smoke...I start coughing'* Sally 11

*'You will have to ask my grandma that as I have no idea how often I have my inhalers'* Sally 11

*'I will go and wake my grandma if my asthma starts up during the night.'* Sally 11

*'She is always asking me to put her on a diet and I won't'* Muriel, grandmother of Sally 11

*'I will say to her you can take your medication if you want but you know it has side effects, just try sitting down for a few minutes'* Muriel, grandmother of Sally 11

*'I have a review in January and I will go back and say the medicine is not working properly'* Muriel, grandmother of Sally 11

Sally acknowledged that she likes to share decisions with her grandmother but demonstrated a lack of confidence in her own ability to make a right decision.

*'I sometimes don't like making decisions because I could make the wrong decision. I like to share decisions with my grandma because I could make the wrong decision'*

Sally 11

*'I will say have you taken your medication and it is usually yes'* Muriel, grandmother of Sally 11

*'I am there for her but I am not on her back'* Muriel, grandmother of Sally 11

*'If I happen to be in the kitchen when she is spraying then I will watch her'* Muriel, grandmother of Sally 11

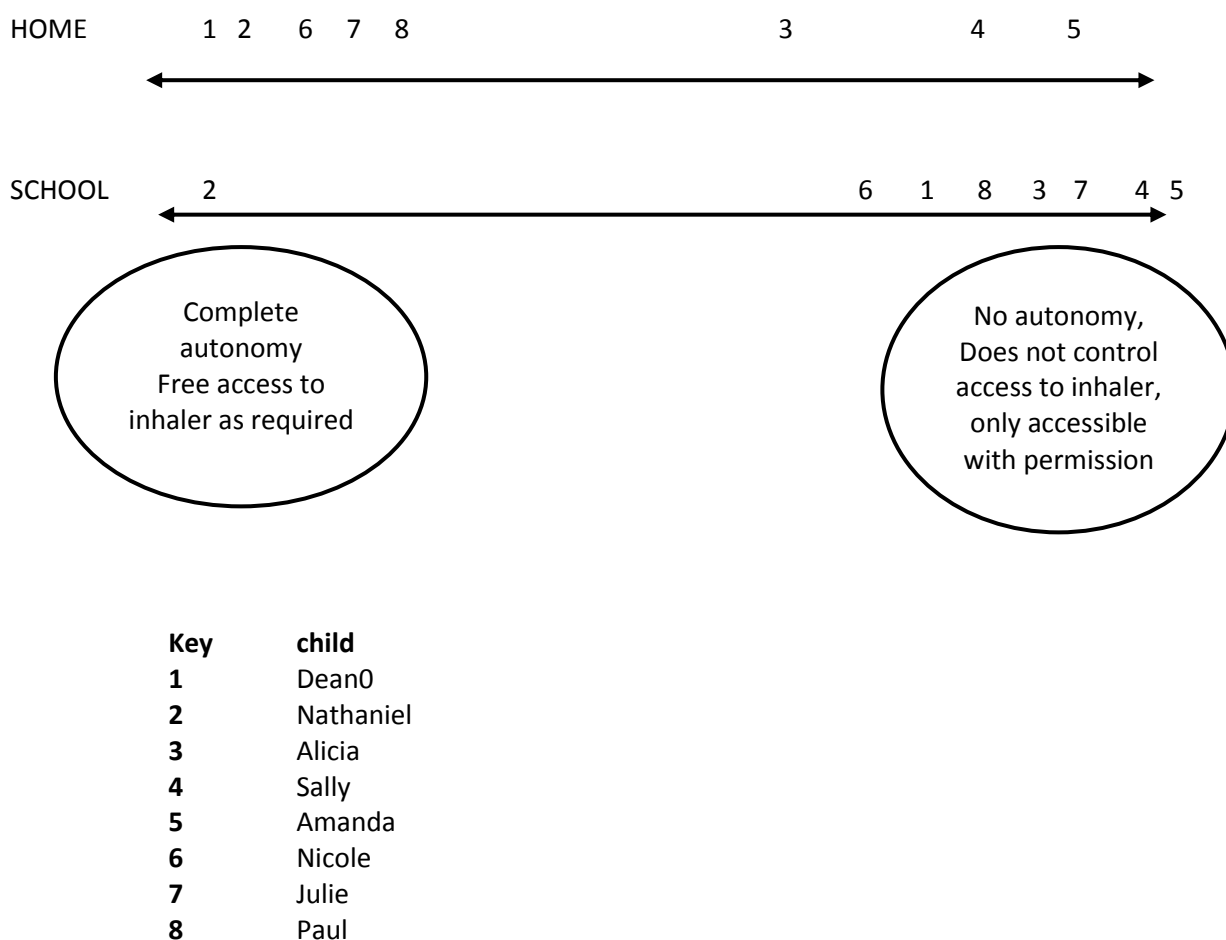
Although Sally reported that she takes her inhaler every morning and night she requests that I ask her grandmother how often she has her inhalers, which suggests maybe Sally does not regularly take her medication. The presence of a daily cough suggests that Sally's asthma is not controlled (SIGN, 2011). Muriel indicates control by describing asthma as *'I have a review'* not Sally indicating responsibility for the asthma is with her. Sally refers to herself as *'acting-up'* in the presence of asthma symptoms not the actual asthma condition, suggesting asthma is viewed as a negative problem. Sally's grandmother demonstrates an authoritarian parenting style, even though she appears to allow Sally to make autonomous decisions she covertly dominates the decisions, controlling access to inhalers and discouraging use of medication. Sally is one of the children from the upper age range and demonstrates least agency alongside Amanda (age 9) suggesting chronological age is not an indicator of increasing child agency and confidence in asthma management decisions. However, authoritarian parenting style does impact on the child's ability to develop confidence and agency for asthma management.

## **6.7 Accessibility of inhaler and reduced autonomy**

Sally had reduced agency as a result of her inhaler being not accessible and controlled by her grandmother. This theme brings together different children's experiences to demonstrate how agency in decision-making and autonomy is certainly reduced when access to inhalers are limited, in particular school appears to be an environment which discourages and

impinges on a child's ability to make an autonomous decision to self-manage their own health.

**Figure 12: Child accessibility to inhaler: school versus home**



### **School reduces child agency and self-management**

Child agency can be affected by the environment. The family maps (Figures 4 – 11) demonstrated how the relationship with a parent can hinder or support the child's agency. The following extracts present findings of how the school systems can also hinder or support the agency of a child, where in a different context is able to self-manage asthma care decisions:

*'I have my own 'carry case' for my inhalers. I take my inhaler when I am wheezing or coughing. Running can start my asthma off so I will ride my bike whilst my mum and sister run. Brown inhaler (preventer) is morning and night and my blue (reliever) inhaler is 20 minutes before exercise... need to ask my teacher if I need my inhaler at school because they are kept in her drawer. The teacher makes sure we all take our inhalers outside when we are doing P.E'* Nicole 11

*'She is in charge of her preventers and inhalers. She has been doing it for about 12 to 18 months. She doesn't avoid specific triggers. She will just use her inhaler if symptoms start following exposure to the trigger. The accessibility of her inhalers probably started the self-management'* Jillian, mother of Nicole 11

Nicole and her mother acknowledge that Nicole is able to demonstrate agency in all aspects of decision-making for their asthma management but Nicole's extract highlights how the school processes 'thins' the agency she is able to demonstrate. Nicole has the self-efficacy belief and her mother has the confidence in her daughter's ability, to make autonomous decisions regarding asthma management.

The following extracts are from children across the age range and their parents. The child is able to decide their symptoms are related to their asthma and have made an autonomous decision to administer their medication. However, in all scenarios (except Nathaniel's) the child's agency is 'thinned' by the school system policy of putting the inhaler in a 'safe place', the child has to ask permission from the teacher to obtain their inhalers. As illustrated within the following extracts:

*'If you wanted your inhaler you would just ask miss'* Dean 7

*'If I start coughing at school I would tell the teacher and she would ask me which inhaler do I need. I have my inhalers on the shelf at school'* Julie 8

*'My inhaler is kept in a box on the windowsill at school. The teacher sends you in for it. I do my inhaler myself'* Paul 8

*'My inhaler is kept in the first aid bag at school. I was in the playground and I needed my inhaler so me and my friend went up to class and asked if I could take my inhaler'*  
Nicole 11

*'If I was at school I would tell my teacher I needed my inhaler and she would go and get it for me and she would do it'* Amanda 9

Parents do not challenge the 'thinning' of the agency within the school setting and are aware their child does not have access to their inhaler demonstrated within the following extracts:

*'She has been coughing in assembly and asked her teacher for her inhaler'* Kirsty, mother of Amanda 9

*'At school they have their inhalers in a box and so he would have to go and ask the teacher first'* Susan, mother of Dean 7

*'I always say it is her decision but she needs to ask her teachers for her inhaler'* Louise, mother of Julie 8

Nathaniel is the only child to have accessibility to his inhalers at home and in school facilitating his autonomous treatment decisions. Nathaniel and his mother Jenny, both agree on Nathaniel carrying his own inhaler as they are both confident in his inhaler use, illustrated within the following extracts:

*'I just make sure he keeps his inhalers with him at all times. He can cope with it at all times'* Jenny, mother of Nathaniel 11

*'I normally have an inhaler with me so I would just use it. I don't mind taking the inhaler in front of my friends. When I have taken my inhaler after about 5 minutes my lungs don't hurt anymore so I know I have taken it properly'* Nathaniel 11

These extracts demonstrate the changing autonomy for decision-making when the inhaler is not accessible. A 'thinning' of Dean's agency is clearly demonstrated within the school setting. These findings reinforce school systems diminish instead of assisting self-management and the school nurse needs to take action on this issue and educate the school staff.

## **6.8 Summary**

The deeper exploration of decision-making under the influence of different factors indicates that decisions are often shifting between a child and their parent as they develop confidence

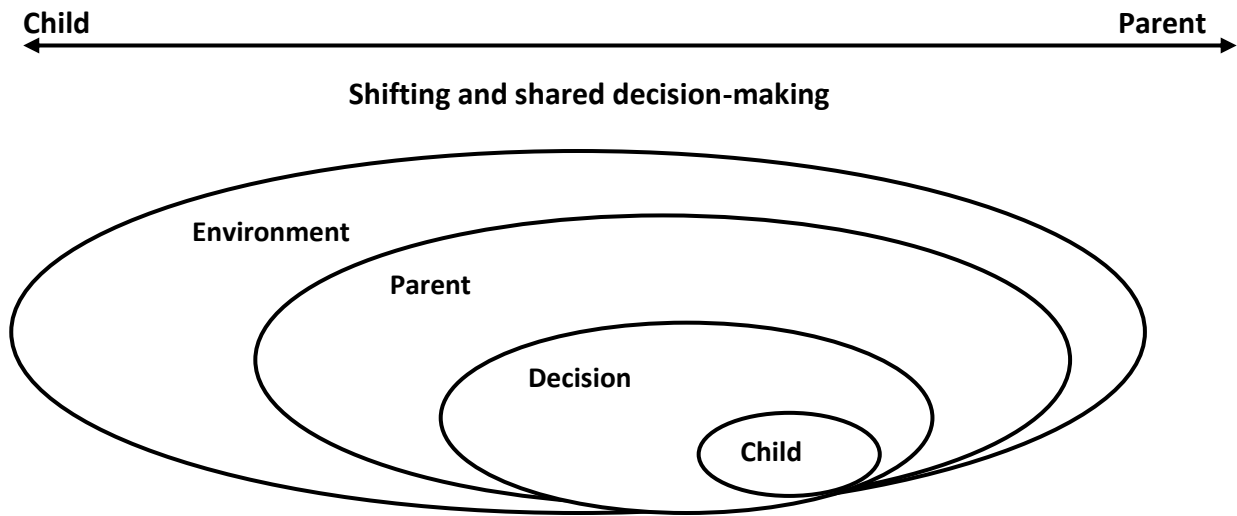
and independence in decision-making. This study highlights that the transition of decision control fluctuates, it is not one directional or static, but influenced by a number of contextual and family characteristics and can move iteratively between a child and the parent.

The findings were drawn from the interview data of seventeen participants although a concentrated cohort the plethora of information gathered from the in-depth interviews was extremely honest and enlightening. Vital information regarding decision-making between children and parents can be gleaned from these varied family experiences to inform discussions in clinics with family dyads looking to foster and develop child agency towards asthma management decision-making. The study demonstrated child and parent decision preferences for the control of asthma management decisions have been highlighted, demonstrating how decision control was a shifting and shared process dependent on contextual factors.

The contextual factors resonate with the theory of interlinked layers of the ecological/family systems theory (Bronfenbrenner, 1979). The child is at the centre of the decision-making process. The surrounding layer 'microsystem', highlights how the child's everyday experiences influences their level of decision-making participation. The next layer, 'mesosystem', represents the parent influencing the child participation. The outer layer, 'exosystem' represents the environment and the many influences affecting the child participating within the decision. Figure 13 illustrates how context is interlinked and affects the child, at the centre of the decision.

The findings are now discussed and appraised in Chapter 7 alongside the current evidence of child decision-making and cognitive development theories to fully explore the impact and new knowledge, uncovered from this study, that will impact directly on nurses and health care professionals advising and guiding families surrounding long-term asthma management.

**Figure 13: Contextual influence to child decision-making**



**Key:**

## Contextual influences

**Child**

## Decision

**Parent**

## Environment

Factor

Cognitive development, self-efficacy, locus of control, experience.

Type of decision: 'who', 'what', 'when', 'why'.

Parenting styles, confidence in child's ability, presence/absence.

Home, school, locus of control.

## **7. Introduction**

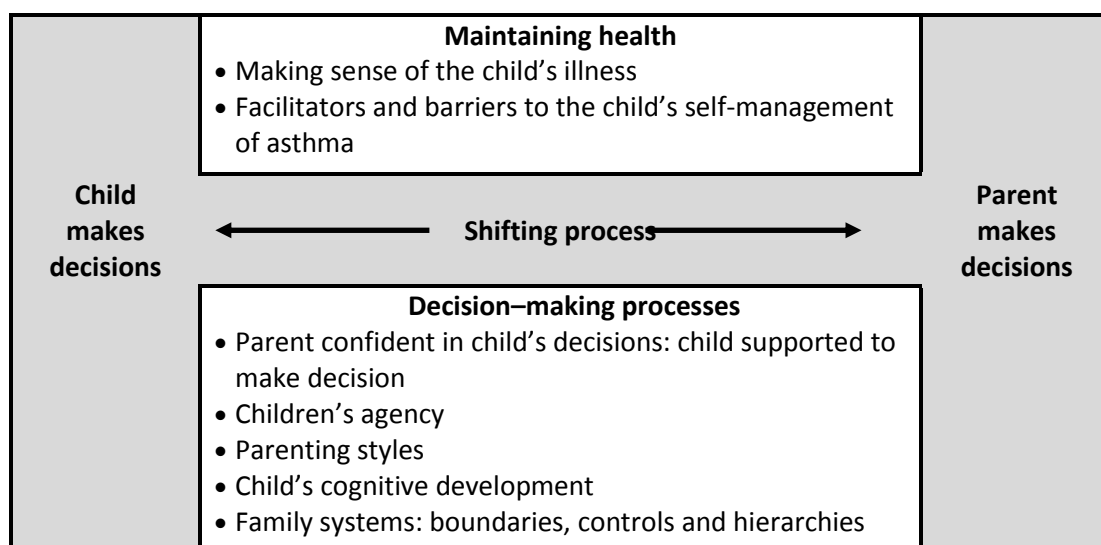
This chapter offers a synthesis and critical analysis of the findings reported in Chapters 5 and 6, which presented children and parents' perspectives of shared asthma management decisions and the contextual factors that influence sharing decisions. The discussion is presented in three sections; first the conceptual framework that represents the way children and parents share asthma management decisions is outlined. Second, the core dimensions within the conceptual framework, 'maintaining health' and 'decision-making processes', are compared and contrasted with existing research presented in Chapter 3, that focused on child and parent shared decisions for the management of childhood long-term conditions. In addition, the theoretical perspectives that underpin the thesis, presented in Chapter 2, which offered potential explanations of the way children and parents approach decision-making, are discussed in relation to the findings. Finally, sharing or shared decision-making between children and parents as a dynamic 'shifting process' is critically evaluated.

### **7.1 Sharing or shared decision-making: development of the conceptual framework**

The conceptual framework presented in Figure 14 represents a dynamic model of the way children and parents share asthma management decisions. The conceptual framework integrates the findings from children's and parents' accounts of the factors that enable or hinder the sharing of the asthma management decisions presented in Chapters 5 and 6 and the theoretical perspectives outlined in Chapter 2. Although the notion of children making health-related decisions that affect them has threaded throughout this thesis, the framework recognises that neither the child nor parent have complete autonomy over the asthma management decisions, but that the decision-making is a dynamic shifting and shared process, dependent on contextual factors and child and parent preferences.



**Figure 14: Revised conceptual framework of child-parent shared decision-making for asthma management**



The conceptual framework reflects that as children gain knowledge and experiences they begin to take more responsibility for their condition, with parents recognising their child's developing role in managing the condition. The shifting responsibility for asthma management decisions is not a linear process that transfers from parent to child; whether the child or parent dominates, decisions shifts and changes across contexts and individual child and parent preferences. More importantly, embedded within this conceptual framework is the notion that in many instances managing asthma decisions is a shared process, with decisions driven by the child's developing autonomy and maximising the child's health and wellbeing. The core dimensions within the conceptual framework, 'maintaining health' and 'decision-making processes' are now presented.

## **7.2 Maintaining health**

Parents develop considerable expertise in managing their child's asthma and through experience become highly responsive to their child's needs (Cashin *et al*, 2008; Maltby *et al*, 2003). Ultimately parents living with a child with a long-term condition, including asthma, want to optimise the child's health and development and minimise the physical, psychological and social impact of the condition for the child (Iley, 2014; Cashin *et al.*, 2008;

Dickinson *et al.*, 2006; Maltby *et al.*, 2003; Balling and McCubbin, 2001). As the child develops, facilitating them to become autonomous in making decisions about their asthma is central to the future management of their condition. The core dimension of 'maintaining health' within the conceptual framework was associated with two concepts labelled; 'making sense of the child's illness' and the 'facilitators and barriers to the child's self-management of asthma', which are now discussed.

### **7.2.1 *Making sense of the child's illness***

For children and parents making sense of asthma involved understanding asthma in terms of illness symptoms and the factors that exacerbated symptoms, responding to acute asthma episodes and understanding and adhering to treatment regimes. Research has found that parents of children with a long-term condition, including asthma, develop the skills to respond to their child's needs and maintaining treatment regime become an integral part of family life (Cashin *et al.*, 2008; Heaton *et al.*, 2005; Ray 2002). Parents' desire to making sense of their child's illness in order to manage illness symptoms mirrored the findings reported in Chapters 5 and 6, where responding to asthma related symptoms and ensuring their child developed the skills to manage their asthma dominated parents' accounts. Parents recognised that they could not be present to monitor their child's condition constantly, therefore developing their child's knowledge and skills were essential to effective management of the condition.

Research has found that young children have the capacity to understand how their body functions (Borzekowski, 2009), the meaning of illness in term of the impact on their lives (Miller, 2009; Oakley *et al.*, 1995) and want to be involved in treatment choices (Miller, 2009). The findings of the present study identified similarities in relation to the children's understanding of their condition and treatments. However, children in the younger age range may not fully understand the complexity of treatments for example, are more likely to understand treatments in relation to the colour of the inhaler, rather the actual inhaled drugs (Pradel *et al.*, 2002), resonating with the findings of the study presented. However, in general young children are able to understand complex health information if presented in an age-appropriate way (Borezowki, 2009; Alderson *et al.*, 2006a; Alderson *et al.*, 2006b; Donaldson, 1978). Health care professionals should regularly discuss with children and

assess their understanding of the purpose of different inhalers to support the child to effectively manage their asthma and contribute towards management decisions (Pradel *et al.*, 2001).

Previous research with children seven to eleven years of age has highlighted that children may omit their medication in school because they do not want to be 'singled out' and 'made to feel different' from peers (Miller, 2009; Alderson *et al.*, 2006b; Meng and McConnell, 2002). Children's accounts of making sense of their illness in the study (Chapters 5 and 6), clearly described the limitations and restrictions of their condition but the children also identified management strategies including those relating to asthma triggers to maximise their participation in leisure activities with peers. For example, children described how they made choices and modified activities, such as running at a slower pace, to limit the impact of the condition on their life and school activities. The influence of peer acceptance on the decisions children make in relation to their condition is consistent with previous research (Meah *et al.*, 2009). Children seven to eleven year old appear to already be developing decision-making skills in relation to their condition. The range and type of decisions increases with cognitive development, with the deliberate choice not to adhere to asthma medication increasing during adolescence (Williams *et al.*, 2007). Risk taking behaviour is particularly associated with the development tasks of adolescence, where the young person begins to exert more authority and control over decisions, including health decisions that affect them (Beck, 1999; Giddens, 1999). This risk taking behaviour can result in potential conflicts with parents (Williams *et al.* 2007). Understanding the reasons children make choices about their asthma have implications for the way parents support their child to manage their condition and the way health care professionals educate the child about the potential consequences of not complying with asthma medication.

In young children, maintaining treatments is primarily the responsibility of parents with a gradual shift of responsibility throughout childhood to the child and ultimately the young person manages their condition autonomously, albeit with family support. In addition to developing the knowledge and skills needed to meet their child's needs, parents recognised that a child with established care management routines during pre-adolescent years are more likely in the long term to adhere to their treatment regime (Chisholm *et al.*, 2012;

Miller, 2009; Miller and Drotar, 2007). Children's accounts across the age range (Chapters 5 and 6), described being confident in a range of asthma management decisions, including making decisions about trigger avoidance, responding to acute asthma symptoms and treatment decisions. Research has identified that children are also aware of when they require support to manage their asthma and confirm decisions made (Pradel *et al.*, 2001). Seeking assistance in managing asthma management decisions is consistent with Vygotsky's (1978) 'zone of proximal development' theory. For example and in relation to asthma management, a child may be able to participate in decisions about asthma management outside the parameters of their level of cognitive development if supported and guided through shared decision-making with their parents. Children, in the present study described that they valued and enjoyed sharing decisions with their parents.

Theory-based psychological models such as the health belief model (Becker, 1974), outlined in Chapter 2, offer explanations about how individuals respond when confronted with a health related problem; asthma management behaviours will depend on how the child or parent balance the benefit and risk associated with management decisions. Health care professionals should recognise the impact health education has on managing the condition will vary according to the importance of the management decision and family priorities at a given point in time and in different contexts (Williams *et al.*, 2007). For example, if a parent smokes cigarettes, a trigger for asthma symptoms, a young child may endure the symptoms knowing it is exacerbating their asthma. A reluctance to articulate their concerns with their parent might be that the child recognised smoking is a coping mechanism for their parent. Findings within Chapters 5 and 6, mirrors previous research, which suggest that parents do not always adopt preventive strategies, such as continuing to smoking despite knowing smoking may exacerbate their child's asthma symptoms (SIGN, 2011; Austin *et al.*, 2005). It has been suggested that observing parent's lack of trigger avoidance may consequently influence the child's future behavioural decisions, positively and negatively, in relation to trigger avoidance (Meng and McConnell, 2002). Health care professionals need to sensitively address issues relating to asthma triggers with the family and discuss strategies for negotiating and reducing the risk of the child experiencing an acute asthma episode.

Shared decision-making for asthma management in children between seven and eleven years of age is important because the child is learning causal relationships between specific triggers, their asthma symptoms and the treatment decisions. Research has identified that the child who is younger than eight years of age can recognise illness symptoms and the need for medication but is unable to make an autonomous decision for specific trigger avoidance (Buford, 2004). However, research also suggests that about one third of children aged between seven and twelve years of age do not make decisions about trigger avoidance, relying on prompts from parents, suggesting chronological age is not a salient factor to making autonomous decisions (Meng and McConnell, 2002; Pradel *et al.*, 2001). These findings are in contrast with those presented in Chapters 5 and 6, where children from the lower age range described autonomous decision-making in response to specific asthma triggers. Consequently, chronological age is not appropriate when considering whether a child is able to share or make autonomous decisions and that decision-making abilities will be context specific. In addition, listening to and valuing children's accounts of their illness and how they contribute to health decisions could support children to develop effective decision-making processes in the future.

### **7.2.2 *Facilitators and barriers to child's self-management of asthma***

The findings provided examples of the range of decision-making styles that operated between and within families, from child dominated decisions, shared and sharing of decisions, through to parent dominated decisions. A range of factors influenced *where*, *when* and *who* dominated the decision-making and when decisions were more likely to be shared. The severity of illness appears to be a significant factor in relation to who dominates decision-making. Severity of illness has been highlighted as a barrier to facilitating children to making autonomous asthma management decisions because an acute asthma episode is potentially life threatening, with parents assuming the role of decision-maker (Taylor *et al.*, 2009; Miller, 2009; Newbould *et al.*, 2008; Williams *et al.*, 2007). However, children's accounts suggest that during an acute asthma episode children can make decisions in relation to administering supplementary medication and may or may not, choose to inform their parents of their management decision. Although children may not require assistance in making the decision, particularly in the absence of parents, many children reported that they

wanted to share with their parents the decisions they made. Research has highlighted that children often include their parent in the decision-making process but that this does not necessarily mean they do not have the knowledge and skills required to make an autonomous decision (Miller, 2009). Indeed, the children within this study reported feeling obliged to involve parents, specifically their mother, in treatment decisions if their parent was present. Parents' presence appears to influence children's autonomous decision-making.

Children and parents report discord in relation to care responsibilities, particular areas of tension include whether the child can access their inhaler without parent permission and participating within physical activities, (Fereday *et al.*, 2009; Cashin *et al.*, 2008; Alderson *et al.*, 2006b; Meng and McConnell, 2002; Pradel, 2001). Findings within this study supports previous research, but also found that for many, children and parents minimise potential care management differences by sharing and discussing decisions. However, the way decisions were shared decision-making preferences were influenced by perceived locus of control. Locus of control for both the child and parent presented as either a barrier of facilitator of children sharing the decisions of their asthma management (Miller and Harris, 2012; Fereday *et al.*, 2009; Williams *et al.*, 2007; Meng and McConnell, 2002). Children with a strong internal locus of control, fostered by their parent's encouragement, enabled their active participation within the management decisions (Miller, 2009; Meng and McConnell, 2002; Fereday *et al.*, 2009). The children's accounts identified that some children had a strong locus of control and described being confident in making decisions about their asthma.

In contrast, parents who retain control of the asthma management decisions were identified as a significant barrier for the child to participate in decision-making processes (Miller, 2009; Taylor *et al.*, 2009). Findings of this study have highlighted that parents that adopt an authoritarian parenting style (Figure 6, p149; Figure 11, p165) were very likely to retain control of asthma management decisions without any explanation of the decision to the child. In contrast with parents adopting an authoritative (Figure 5, p146; Figure 8, p156; Figure 9, p159) or permissive parenting style (Figure 7, p152; Figure 10, p162), and were more likely to encourage the child to exercise autonomy within the day-to-day management

decisions of the asthma. The salient differences between the decision-making in permissive and authoritative parenting style was the dominance or submissiveness of the parent. In permissive parenting the child was given control of the decision regardless of the child's decision-preference. In authoritative parenting the child was allowed to demonstrate agency but the parent's decision remained dominant. However, there was often reciprocal sharing of decisions or decisions were shifted back into the domain of the parent if the child was unable to manage the decision, for example the severity of an acute asthma episode or in the presence of additional or new symptoms.

Outside the home environment teachers are the main adult support available to children and therefore have the potential to influence the management of childhood asthma (Gabe *et al.*, 2002). However, research has identified that systems and policies that operate with schools in relation to managing long-term conditions can disempower children from making asthma management decisions (Cashin *et al.*, 2008; Meng and McConnell, 2002). Figure 12 (p169) highlights how the child's autonomy is reduced within the school setting, due to the inaccessibility of their inhaler. The findings highlight the child is able to make the autonomous decision that their symptoms are associated with asthma and in need of their asthma medication. However, due to a lack of inhaler accessibility disempowers the child's agency as the school teacher issues the child with their inhaler for them to self-administer. These findings resonate with previous research of children reporting concerns about the inaccessibility of inhalers within the school environment (Cashin *et al.*, 2008; Meng and McConnell, 2002; Sandsund, 2011). Findings from previous studies suggest that in general teachers appear to lack knowledge and understanding of asthma. Insurance concerns may be a contributory factor in relation to teachers declining to administer specific health care interventions, with over 80% of teachers not aware they have local authority indemnity (RCN and UNISON, 2012). Lack of policy, guidance and poor operational systems have been attributed to the reasons there is lack of support for children to manage their asthma in the school environment (RCN and UNISON, 2012). For example school policies determine where children's asthma medication is stored and influence the child's ability to manage their medication independently.

There appears to be a lack of collaborative working between children and parents, school staff and health care professionals in relation to meeting the needs of a child with asthma (RCN and UNISON, 2012; Meng and McConnell., 2002). Each child with a long-term condition should have an individual care plan in the school environment to facilitate optimum health of the child and to teachers and school staff of the actions required should an acute asthma episode occur (RCN and UNISON, 2012). The majority of children with long-term conditions do not have an individual care plan (RCN and UNISON, 2012), with some studies reporting that as few as 3% of children have this resource in place (Roberts and Campbell, 2013). There is a need for greater educational input for teachers in relation to asthma management and supporting children to make decisions about their asthma management, which can be facilitated by ensuring children have an up to date personal asthma action plan, as advocated within the Every Child Matters guidance (DfES/DH, 2005, 2004a, 2004b). This plan should be developed in collaboration with the child, parent and school nurse and shared with the school staff. School nurses and teachers should identify training needs in order to ensure care plans can be met. The administration of medication within the school has been identified as an important aspect of care within individual care plans for children with a long-term condition (RCN and UNISON, 2012).

The number of school children with asthma is 1.1 million (NICE, 2013; Asthma UK, 2010a). Chapter 1 highlighted that two thirds of school staff do not feel confident in managing an acute episode (Sandsund, 2011; Reading *et al.*, 2002). A recent UK nationwide survey identified only a third of school staff members had received appropriate training from a health care professional in relation to managing an acute asthma episode (RCN and UNISON, 2012). In 2002, schools were required to ensure inclusive learning for children with complex health needs and the schools role has evolved to include the provision of health care support care to children with particular health needs (Rehm, 2002). The current financial climate has resulted in cost reductions across essential services, including health and education. Despite the financial cost constraints schools have a duty of care to ensure pupils are safe and receive well planned health care within the school setting. Children and their parents need to feel safe when a large proportion of a child's day is spent within an education setting.



Likewise, education staff need to feel confident and competent when administering health care support to the child.

As already highlighted within Chapter 2, five preventable child deaths occur on a daily basis due to asthma, meningitis and pneumonia (Roberts and Campbell, 2013). Incidents of children dying because of lack of access to asthma treatments, as a consequence of school system policies, should not occur (Roberts and Campbell, 2013). Guidance on managing medicines in schools advocates that a child retain their inhalers and are enabled to use the inhaler as required (Department for Education and Skills/Department of Health, 2005).

However, research presented in Chapter 3 (Cashin *et al.*, 2008; Gill and McNeish, 2006; Tates *et al.*, 2002; Stohlfer *et al.*, 1998) and the findings from this study (Chapters 5 and 6) identify children retain their inhalers in breach of school policies. In addition, research has highlighted that parents often encourage their child to retain their inhalers despite this practice breaching school policies (Cashin *et al.*, 2008). If the child and parent perceive the child has the cognitive ability to make independent treatment decisions, inhaler accessibility should be encouraged by the school. However, as the findings highlight not every child will have the knowledge and have developed the decision-making skills to make autonomous decisions about their asthma, therefore require support from a responsible adult.

School policies in relation to asthma management, do not appear to accommodate the individual child's decision-making abilities or preferences (Cashin *et al.*, 2008; Newbould *et al.*, 2007; Meng and McConnell, 2002). Unless policies reflect the developing skills of children in relation to managing their asthma, delays in treatment administration and children operating outside school policies will continue. The findings from this study presented suggest that there remains a gap between policy and practice and that health and education systems still lack cohesion. In addition, developments in the social construction of childhood and concepts such as the child as an agent enacted through policies, laws and social practices (James and James, 2012; Lambert *et al.*, 2011; DH, 2007; DfES/DH, 2005, 2004a; 2004b; DG, 2001; United Nations Convention on the Rights of the Child, 1989) have not necessarily included the child with a voice in matters that concern them (Lloyd-Smith and Tarr, 2000).

### 7.3 Decision-making processes

Examples of the range of decision-making styles that operated between and within families has been highlighted in the family maps presented in Chapter 6. The core dimension of 'decision-making processes' outlines the way in which child-parent decision-making operates and was influenced by the concepts labelled: 'parent confident in child's decisions: child supported to make decision', 'children's agency', 'parenting styles', 'child's cognitive development' and 'family systems: boundaries, controls and hierarchies', which are now described.

#### 7.3.1 *Parent confident in child's decisions: child supported to make decision*

The findings of this study (Chapters 5 and 6) and the literature reviewed (Chapter 3), identify that significant contributing factors of a child's autonomous decision-making for the management of their long-term condition are: self-efficacy (Kieckhefer *et al.*, 2009); cognitive development (Miller and Harris, 2012; Miller *et al.*, 2008; Newbould *et al.*, 2008; Pradel *et al.*, 2001); and parental confidence in their child's ability to self-manage decisions (Meah *et al.*, 2009). Similarly, the findings of this study and the literature reviewed (Chapter 3) suggest that the child's chronological age has been over emphasised as a significant contributing factors of a child's autonomous decision-making (Buford, 2004) and is a criticism of Piaget's (1969) stages of cognitive developmental (Myant and Williams, 2005). However, it is important children are not coerced into becoming the sole decision-maker until they feel ready to make autonomous decisions. A sharing of decisions is more likely to help children to develop good decision-making strategies in the future. Therefore, parents, health care professionals and school staff should guide and support the child to make autonomous management decisions when 'the time feels right' or when the child is demonstrating cues for autonomous asthma management tasks. This is particularly salient when the child is experiencing asthma symptoms such as a cough and needs to alert their parent to 'hidden' symptoms, without the responsibility of autonomous decision-making. The accompanying 'tight chest' enables the child to distinguish between a common cough and an asthma cough, a symptom the parent is visually unable to detect (Cashin *et al.*, 2008; Meng and McConnell, 2002). Shared decision-making will enable the child to alert their parent to symptoms and management decisions are able to be shared without the child

having actual decision-making authority (Joffe, 2003). Indeed, the findings highlight that children and parents enjoy making decisions together, with children influencing the decisions made while sharing the responsibility with their parent. Children feel valued when they are involved in decisions about their own health.

Transferring care responsibility to the child can be aided by facilitating child-parent shared decision-making (Miller and Harris, 2012; Miller, 2009; Fereday *et al.*, 2009; Miller *et al.*, 2008). The findings suggest that a child between seven and eleven years prefers to manage their own decisions during leisure activities; as previously highlighted this provides the child with control to continue activities with their peers. However, tensions may result when a parent limits their child's participation in physical activity (Fereday *et al.*, 2009). The findings of this present study identified even though a parent lacked confidence in their child's ability to manage asthma decisions it did not influence supporting their child to make future management decisions. For example, awareness that a child was not taking their preventative inhaler does not necessarily result in the parent taking control of the decision, but parents often used prompts until the child resumed administering their regular preventative medication (Susan, mother to Dean, 8). In a second scenario a child repeatedly lost his reliever inhaler, again the parent did not resume control of this aspect of care but allowed the child to retain control of the inhaler and over time the child became more responsible for the safe keeping of his reliever inhaler (Jenny and Peter, parents to Nathaniel, 11). In these examples, if the parents had over-emphasised a lack of confidence in their child's ability to manage the management tasks and automatically resumed control of the decision, the child may have lost confidence in contributing to managing their condition. Previous research has identified children can be frustrated and feel undermined when parents constantly remind them of the need to adhere to treatment regimes, with a resulting loss of control in managing their condition (Meng and McConnell, 2002). Similarly, parents have expressed frustration when constantly prompting the child to actively manage their condition (Miller, 2009; Buford, 2004; Meng and McConnell, 2002). Parents' prompting of asthma treatment decisions is driven by the risk of asthma symptoms deteriorating. Research has highlighted that some children wait until they are no longer able to manage the acute asthma episode before alerting their parent which can result in delayed treatment

(Hafetz and Miller, 2010; Miller, 2009). The study findings presented did not identify any child or parent frustrations due to parental prompts of treatment decisions, instead the children and parents highlight strategies they employ to alleviate any contentious decisions. For example, Louise, Julie's (8) mother acknowledges her daughter is 'stubborn' and so to avoid a potentially contentious situation with Julie, she will contact the school instructing they administer Julie's preventative inhaler. Although, the findings did highlight parents prompted management decisions, usually for the administration of reliever or preventative inhalers, often children and parents manage decisions in collaboration; sometimes the child taking control of decisions and sometimes the parent taking control of decisions, but often decisions were shared. Current health models describe the management of long-term conditions in children as either being professional led (Cashin *et al.*, 2008; Charles *et al.*, 1997) or parent led (Newbould *et al.*, 2008; Williams *et al.*, 2007; Buford, 2004), which does not recognise the role of the child-parent relationship in managing their condition. Typically the child's 'voice' is lost and the parent perspectives dominate.

### **7.3.2 Children's agency**

Children's Agency (Valentine, 2011; Hedges, 2012; James, 2007; Mayall, 2002) and the notion of 'thick' and 'thin' agency (Klocker, 2007; p85) is useful to understand the way children engage with the management of their long-term condition and begin to share care decisions with parents. For a child becoming an agent for their own health needs is influenced by the way the family system operates (Bronfenbrenner, 1979). Children's agency fosters children to make a positive contribution to decisions that affect their life (Valentine, 2011; Hedges, 2012; Moules *et al.*, 2009; James, 2007; Mayall, 2002) and supports overarching themes across child health policy, particularly the '*Every Child Matters*' agenda (DH, 2004a; 2004b). The findings of this study mirror the research reviewed in Chapter 3 in relation to how children's agency is facilitated by the child's competence to make decisions for their asthma management. Although it is acknowledged agency is not the same as competence, sharing care decisions enabled a child to demonstrate agency within their asthma management decisions, without the responsibility of the consequences of a 'wrong' decision (Valentine, 2011). A child's self-efficacy belief will 'thicken' their participation within the decision-making and consequently provide the experience and

knowledge for future asthma management decisions. Findings supported the self-efficacy belief that *'one's judgement of one's capabilities to organise and execute courses of action required to attain designated types of performances'* (Bandura, 1986; p391) and that *'self-efficacy is represented by criteria that encourage participation and taking ownership of the consultation'* (Milnes *et al.*, 2013; p95). A child's confidence in their ability to make decisions will facilitate participation within asthma management decisions. Although Milnes *et al.* (2013) study used a sample of young people aged thirteen to nineteen years, focussing on their participation within the asthma review consultations with a practice nurse, the findings resonate with the study findings, which suggest self-efficacy influences children's participation in matters that concern them, including asthma management decisions. However, the findings also highlight that self-efficacy is not a fixed trait and varies across situations helping to explain the shifting and shared decision-making within the revised conceptual framework of child-parent asthma management decisions. Children reported they do manage their own asthma and make decisions about treatments and asthma triggers but value seeking parent support.

Buford's (2004) grounded theory study identified two discrete stages of parent to child decision-making for asthma management and two levels of child participation within decision-making processes: 'being informed' and 'being the main decider'. However, the child and parent findings presented in Chapters 5 and 6 identified the transition of asthma management decisions from parent to child control in children seven to eleven years of age did not occur but that decisions were more likely to be a shared process. Care decisions for children are seldom made in isolation, there is usually a reliance on another individual, for example parent, friend and teacher (Coyne and Harder, 2011; Coyne *et al.*, 2006). Even a child that demonstrates being a competent autonomous decision-maker values sharing decisions and gain the support of others, particularly parents (Miller, 2009; Coyne *et al.*, 2006), which mirrored the findings presented in Chapters 5 and 6. The child-parent decision-making process is not a linear process following a trajectory from transferring the responsibility for asthma management parent to child, as Buford (2004) suggested. Instead the findings from the study presented as part of this thesis identified the decision-making as a *'dynamic shifting and shared process'*. For example, the child and parent accounts

presented in Chapter 6 highlighted that when the child experiences illness in addition to their asthma or the asthma symptoms are more severe there is a shifting of the decision-making process to someone else, usually the mother. It seems inappropriate to expect a child to making asthma management decisions without the support of parents and health care professionals. The key issues are not necessarily about the child having to take responsibility for making decisions but about facilitating the child to develop the skills to make decisions and parents' and health care professionals' understanding the transference and shifting concept of the decision-making in order to support the child. The studies reviewed in Chapter 3 identified that when parents retain control of decisions the child's agency is 'thinned', which could result in the child not appreciating or acknowledging early warning signs of acute asthma symptoms (Miller, 2009; Meng and McConnell, 2002). Similar findings were found in the study presented although depending on child agency and the parenting styles, the child may choose to ignore their parent's advice particularly if the advice was provided by their father. Some parents find it difficult to relinquish the full responsibility of the decisions to their child and retain control for asthma decisions into late childhood (Miller, 2009; Taylor *et al.*, 2009). Previous literature identified gender differences in relation to mother's supporting child agency; mothers are less likely to allow their son to make asthma management decisions compared to daughters (Williams, 1999; Smith, 1998). This was not found in the findings of the study presented.

### **7.3.3 Parenting styles**

The child-parent findings revealed a range of typologies that represent different parenting approaches in relationship to sharing responsibility of the asthma management (Miller, 2009). A detailed overview of different parenting styles was presented in Chapter 2, Section 2.3.3. In summary, parents usually adopt one of four parenting styles: 'authoritarian parenting', 'authoritative parenting', 'permissive parenting' and 'uninvolved parenting' (Maccoby and Martin, 1983:p39-49; Baumrind, 1967:p44). These parenting styles were developed from observing child-parent interactions in a natural environment; these typologies were applied to the child-parent findings presented. Chapter 5 presented a family specific map for each child-parent dyad in order to illustrate the direction of the control of asthma management decisions within the dyads. Three of the four parenting

styles were identified during the stages of data analysis. None of the participating parents adopted the ‘uninvolved parenting’; these parents typically provide minimal care and are not involved in their child’s life (Maccoby and Martin, 1983; Baumrind, 1967). The majority of the parents appeared to adopt an authoritative parenting style, enabling children to contribute and participate within some asthma management decisions resulting in increased confidence to contribute to asthma management decisions albeit the control of the decision remained with the parent. An authoritarian parenting style was evident with two of the parents, where they dominated the decisions allowing the child little or no control over the decision-making process. Consequently, the child had little control in relation to decisions about them. The findings highlight a child living within an authoritarian parenting family did not want to be involved in decisions about their asthma (Amanda and Kirsty). This parenting style typically results in low independence and low self-esteem in the child and a lack of control in relation to participating in the management of their asthma (Maccoby and Martin, 1983; Baumrind, 1967). Permissive parenting style was also evident within the findings; typically these parents facilitated the child to gain control of asthma management decisions, regardless of the child’s decision preferences. The family specific maps in Chapter 6, Section 1. illustrated that parenting styles influenced the control of asthma management decisions. For example, Kirsty, mother of Amanda 9 (page 149) demonstrated an authoritarian parenting style dominating the majority of asthma management decisions. Interestingly, the child reported not wanting to be involved in decisions regarding her asthma management suggesting a lack of confidence. Yet, the extracts (page 126) identify Amanda had the capacity to make decisions. For example, she could identify that a cough is a symptom of asthma and requires treatment, but responded by alerting her mother or teacher relying on them to administer the inhaler. None of the studies reviewed in Chapter 3 discussed how parenting styles may affect a child’s participation within the decision-making for their asthma management. Although, one study highlighted parenting styles may influence collaborative decision-making but did not explore this in any detail (Miller, 2009).

#### **7.3.4 *Child’s cognitive development***

Previous research highlighted a child’s cognitive development influences their ability to participate within the decision-making processes in relation to health decisions (Taylor *et al.*,

2010; Miller *et al.*, 2008; Myant and Williams, 2005). Piagetian (1969) theoretical perspectives about how a child's cognitive development influences their own participation within the decision-making (Chapter 2, Section 2.2) suggests limited decision-making involvement of a child within the seven to eleven year age range, although they are beginning to develop causal relationships between health and illness (Alderson *et al.*, 2006b). Piaget's (1969) concrete operational stage (between seven and eleven years) would suggest that the children within this study would only just be beginning to apply logical thought and reasoning skills to concrete problems, suggesting limited participation within decisions as asthma management issues arise. However, the findings illustrated that a child of seven years of age has the ability to make autonomous management decisions, for example understanding his asthma symptoms will reduce if he modified his running pace (page 127). These findings resonate with previous research undertaken with children of a similar age that also demonstrated autonomous decision-making skills to reduce asthma symptoms through the reduction or avoidance of asthma triggers (Meah *et al.*, 2009).

These types of asthma management decisions require the child to apply complex thought processes to different situations and then make an autonomous management decision. Findings of this present study and previous research (Meah *et al.*, 2009), suggest the application of complex thinking by children when undertaking self-management strategies. Piaget (1969) suggested a child of seven years of age is unable to achieve such complex thinking, supported by the findings of Pradel *et al.* (2001), where some children aged between seven and twelve years did not recognise the warning symptoms and relied on parents to manage their asthma. However, other children could respond to acute asthma symptoms and reduce asthma symptoms through the reduction or avoidance of asthma triggers (Table 13).

Piaget's (1969) cognitive developmental stages and Buford's (2004) transfer of asthma management responsibility from parents to their school-age children model do not capture or account for the variability in decision-making capabilities for children of similar ages. Each child has different experiences and therefore different perspectives on their participation with asthma management decisions. One explanation for the differences may be attributed to societal factors and the interaction with other individuals (Vygotsky, 1978). If a parent and



health care professional work with the child to share decisions within the child's zone of proximal development (Vygotsky, 1978), the child's knowledge and understanding of asthma management will increase. The child's management decisions can be guided and supported in a safe and informed manner; when assisted by a more knowledgeable individual a child may be enabled to achieve tasks beyond their current capabilities. Piaget (1969) argued social interaction hindered cognitive development; in contrast Vygotsky's theory (1978) attempted to explain the variability in a child's decision-making differences. Asthma management decisions were undertaken by children from the lower and upper age range, for example, understanding specific triggers to their asthma symptoms and avoiding, minimising or treating the symptoms when exposed to the trigger.

Research relating to children with long-term conditions, between seven and sixteen years of age, has explored children's involvement in health management decisions (Taylor *et al.*, 2009). According to Piaget's (1969) stages of cognitive development children above 11 years of age are entering the formal operational stage of cognitive development, with a new stage of logical thinking emerging and the child is capable of complex thinking (Sanders *et al.*, 2009; Borzekowski, 2009; Myant and Williams, 2005). Therefore the children's accounts presented in this study who were aged seven to eleven years of age will be different from research undertaken with children over 13 years of age, who will have different perspectives about participating in health decisions. Piaget (1969) postulated that a child moves from each cognitive development stage in a linear order and has to be a certain age before progression to the next developmental stage. Consequently, a child between seven and eleven years of age is only just beginning to apply logical thoughts and reasoning to concrete situations and are therefore thought to be incapable of abstract and complex thinking (1969). Findings from the study presented and previous research (Meah *et al.*, 2009; Newbould, 2008; Meng and McConnell, 2002; Pradel *et al.*, 2001) has found that children between seven and eleven years of age are able to demonstrate abstract and complex thinking in the autonomous decision they accomplish. For example, administration of the preventative inhaler requires abstract thinking and preventive action for symptoms that may occur if they did not administer this medication. However, just because a child is able to demonstrate competence in their inhaler use does not necessarily mean they understand

the association between the symptoms and which inhaler they need to administer. The findings in Chapter 5, Section 5.3.1 highlight that children may acknowledge their inhaler treatment making their decisions on the colour of a blue or brown inhaler. These findings highlight a child needs to be educated on the differences in asthma treatment, which could be undertaken through a regular review within school in collaboration with child, parent, school nurse and key staff member to facilitate a personal asthma action plan is developed, reviewed and amended in line with the child's developing agency. This will ensure the child only takes asthma management responsibilities for decisions when they feel competent.

The child and parent findings provide examples of children from the lower age range demonstrating a similar level of participation within the decision-making process as children from the upper age range. Yet, Piaget's theory (1969) suggests children of this age will require parents to interpret their asthma symptoms, make decisions and implement appropriate interventions. This was not evident within the findings of this study, for many children they contributed and in some situation took responsibility for day-to-day asthma management decisions. However, asthma severity and the presence of additional illness, influence a child's acknowledgement that these decisions may be beyond their cognitive ability and would ask parents for support and guidance in making a decision or taking control of the decision. Parental support of a younger child's participation within the decision-making process enables the child to achieve more complex management tasks (Byrnes, 2005) lending support for Vygostky's (1978) theory and the difference between what a child can do with assistance and what can be achieved independently.

### **7.3.5 Family systems: boundaries, controls and hierarchies**

A dynamic relationship exists between three interlinked layers with family systems theory: 'microsystem', 'exosystem', 'macrosystem', that impacts on how children manage asthma management decisions in relation to boundaries, controls and hierarchies within each layer. The innermost layer, the 'microsystem' directly relates to the child's everyday experiences and includes the family and school. The boundaries, control and hierarchies within family systems influence the level of child participation and facilitating the child to undertake asthma management decisions (Meah *et al.*, 2009; Buford, 2004; Knafl *et al.*, 1996; Bronfenbrenner, 1979).

Typologies of parenting styles have influenced child agency in the decision-making and were presented in Sections 7.3.2 and 7.3.3. Parents are less likely to involve their child within the decision-making if they are tired or other siblings are demanding time in the home environment (Kratz *et al.*, 2009; Miller, 2009), child and parent extracts did not share these findings. One mother, a single parent with three children had limited time to negotiate decision-making with her daughter (Figure 6, page 149), and ‘thinned’ her daughter’s agency by dominating the decision-making. In contrast, another mother (Figure 4, page 143), with work commitments and two children, actively encouraged her daughter to share the management decisions, often with total autonomy and ‘thickened’ her daughter’s agency. These findings suggested that it is not necessarily the parent’s time constraints that affect the decision-making process but the influence of family systems and in particular parenting styles.

Similarly, a daily routine established within the family may enhance the way child-parent decision-making processes are developed (Cashin *et al.*, 2008). Findings described how a father controlled the decision-making by presenting his child with their inhaler at the breakfast table each morning, reinforcing the need to take the medication each morning. However, a learnt behaviour of taking medication is not necessarily a decision but a routine that has been established by the child and parent (Donaldson, 1978). The findings suggested this child did not make an autonomous decision to administer and it is unclear whether the child would make an autonomous decision to administer the inhalers if his father did not place the inhaler in front of the child each morning.

Incorporating the management of the child’s long-term condition within family life can facilitate shared decision-making (Hafetz and Miller, 2010; Kiechefer *et al.*, 2009; Alderson, 2006b). The study findings support family routines facilitating, even a young child’s ability to self-manage their asthma management decisions. One of the children had morning and evening rituals which include brushing their teeth and administering their inhalers. The child successfully managed these management tasks each day. Excluding the child from shared decision-making is associated with reduced adherence outcomes for the management of their long-term condition (Chisholm *et al.*, 2012).

#### **7.4 Child-parent shared decision-making: a dynamic shifting process**

The transition of asthma management decisions from parent to child is not a linear process and not the most appropriate model for children of seven to eleven years of age; a model of child-parent shared decision-making is more appropriate recognising the role of both the child and parent in children's health care. This model recognises the importance of the child's 'voice' regardless of who actually makes the decision (Miller, 2009). Sharing the decision involves the child and parent: sharing information; a mutual seeking and valuing of opinions; and valuing sharing decisions (Miller, 2009:p258). The findings identify children and parents enjoy sharing decisions but previous research has identified children know when adults are paying 'lip service' to including them in participating within the decision-making process (Miller, 2009). The research reviewed in Chapter 3 identified the child's sole responsibility for management decisions occur opportunistically, for example during sleepovers with friends, rather than as a planned process (Newbould *et al.*, 2008; Buford, 2004; Callery, 2003). However, this may not be the most appropriate time for the child's self-management and often results in the child making decisions in isolation from trusted family members or with people who may not know how to respond if an acute asthma episode occurs. Planned shared decision-making in a controlled environment enables the child to have influence and contribute to decisions with guidance and support from their parent or responsible adult (Pradel *et al.*, 2001). More importantly this can facilitate the child to share the responsibility for decisions until a time when they feel ready to 'go it alone'.

The findings of this study identified that some children can take responsibility for decisions outside home that they may defer to parents when at home. Child and parent accounts suggested that when the child's mother is present then an autonomous management decision is less likely. Children reported sharing the decision, when they would prefer to make an autonomous decision, to avoid challenging parent, in particular their mother. These management decisions include: whether to administer the reliever inhaler in the presence of asthma symptoms; how to administer the inhaler; and minimising or avoidance of specific asthma triggers. There were examples when a child shifted the control of the decision back into the domain of their parent. Children report requiring support with 'bigger'

decisions such as when their symptoms are more severe or in situations where they have limited prior experiences (Miller, 2009 p257; Pradel *et al.*, 2001).

The child and parent extracts have highlighted the importance of shared decision-making of asthma management. The children and parents enjoy sharing decisions. The child will generally share the decision if they require support and guidance on a management task they feel is beyond their knowledge and experience. Sharing the decisions does not appear to hinder autonomy or child agency but has a positive effect through the provision of parental support and guidance for effective asthma management. Sharing decisions also reassures the parent, the child has acknowledged their limitations within their asthma management decisions, enabling the parent to share knowledge and increase the child's experiences of asthma management. The child does not necessarily always want agency and may 'shift' the control of the decision back into the domain of the parent if the asthma treatment has not been effective, asthma symptoms are more severe, nocturnal symptoms, when to resume physical activity following symptoms. The sharing of decisions is a reciprocal process benefitting both child and parent.

Health care professionals have to work collaboratively with the child and parent to encourage independence in-line with the child's self-efficacy belief and competence whilst simultaneously addressing child and parent decision preferences. This practice will alleviate contention during the decision-making when the child's cognitive and complex thinking is developing. It is important to recognise the difference between a child requiring guidance and support for the decision-making and when the parent dominates the decision. This allows for an exploration of the scenarios to identify learning opportunities when the child demonstrated agency, when the decision was shared and when the decision was a shifting process. For example, when a child is demonstrating cues to self-management and is able to identify their symptoms are related to asthma, this highlights a learning opportunity for the parent to teach the child to administer the inhaler independently, instead of dominating the decision and administering the inhaler for them. It is important the child and parent express any concerns they may have with the child's developing autonomy of the asthma management, allowing an open discussion and a sharing of experiences with a health

professional to develop strategies with the family promoting safe effective decision-making of the asthma management.

## 7.5 Summary

This study has explored children and parents' perspectives of shared asthma management decisions and identified a shifting and shared decision-making process operated with families of children with asthma. The conceptual model reflects that the most appropriate model for children of seven to eleven years of age is a shared decision-making recognising the role of both the child and parent. This differs from the more widely accepted model of transition of asthma management decisions from parent to child. A central tenet of this thesis has been the concept of 'child agency' and that findings reflect the importance of the child's voice when undertaking research with families. Both children's and parents' accounts are reflected equally during the development of the conceptual framework. The structured literature review in Chapter 3 identified that childhood studies within this topic area have still marginalised the voice of the child (Taylor, *et al.*, 2009; Williams *et al.*, 2007; Buford, 2004). The present study is novel as it has focussed on the child's and the parents' perspectives of the decision-making processes for their asthma management, the younger voice is being heard within the study, unlike previous research on a similar topic (Taylor *et al.*, 2010).

Although the theories outlined in Chapter 2 go some way to explaining the findings presented in relation to child-parent shared decision-making of the asthma management, the most useful theoretical perspectives to explain the findings related to 'child as an agent' (Hedges, 2012; James, 2007; Mayall, 2002) and the family systems theory (Bronfenbrenner, 1979). The child-parent findings revealed a range of typologies that represent different parenting approaches in relation to sharing responsibilities of the asthma management decisions. The different approaches were influenced by:

- Agency demonstrated by the child within the decision-making process of asthma management;

- Control of the decision-making demonstrated by the parent for the child's asthma management.

Although a range of parenting approaches in relation to sharing responsibilities for asthma management with their child are presented, parents' approaches varied in response to contextual factors such as severity of child's illness symptoms, family demands and parenting stress. Consequently, parents' could both facilitate their child's participation within decision-making processes or take responsibility for decisions. Although parenting styles can influence the direction of the asthma management decisions, the child's personality can be a significant factor in relation to becoming an active participant in decisions about their condition (Bernstein, 2011).

## **8. Introduction**

Critically evaluating the research undertaken, reflecting on the research process, and highlighting what could have been better and what was particularly good about the research method is central to assessing the credibility of the findings. This chapter presents the strengths and limitations of the empirical study and the measures undertaken to ensure the findings presented in Chapters 5 and 6 were unbiased, accurate and truthful accounts of children's and parent's experiences within the context of managing asthma decisions, and the potential to transfer the new knowledge to other settings. Central to the issues of achieving valid and reliable qualitative research are accounting for the influences a researcher's personal beliefs impact on the study design and methods, therefore a personal reflexive and reflective account is offered.

### **8.1 Issues of quality and reliability**

There are no accepted standards by which qualitative research is judged, therefore demonstrating the quality and rigour of qualitative research findings is challenging (Rolfe, 2006). In the context of qualitative research: validity relates to the findings accurately reflecting the data (Lewis and Ritchie, 2003); reliability refers to the consistency of the analytical procedures (Long and Johnson, 2000); and transferability relates to the ability to consider whether findings are applicable to other settings (Lewis and Ritchie, 2003; Patton, 1990). The credibility of the study is also dependent on the researcher acknowledging and accounting for personal and research method biases that may have influenced the findings (Sandelowski, 1986). This section describes the measures employed to ensure findings were valid and reliable, and discusses the potential transferability of study findings to other settings.



### **8.1.1 *Validity***

The validity of the study related to accurately representing and interpreting participants' accounts of child and parent decision-making for asthma management. Validity refers to whether the researcher has remained true to participants' accounts, and the findings meet the study aims objectives (Tobin and Begley, 2004; Long and Johnson, 2000). Demonstrating validity was an ongoing process and included: accurately reflecting participant accounts by ensuring data analysis was systematic, transparent and the analytical processes described in detail (Tobin and Begley, 2004); and is one of the strengths of the framework approach as a method of data analysis (Ritchie and Lewis, 2003); providing extracts of participants accounts (Speziale and Carpenter, 2007; Mays and Pope, 1995) and ongoing reflexivity with research supervisors challenged assumptions during data analysis and generation of final themes (Lewis and Ritchie, 2003). The coding index was developed independently by the researcher and two supervisors for example, reviewing two contrasting interviews and discussing coding during supervision meetings until a consensus was achieved.

Acknowledging researcher personal biases is central to the validity of study findings (Long and Johnson, 2000), but a reflexive approach was employed throughout the process of the study, with regards to conducting the in-depth interviews with the children and parents; and when interpreting the data to ensure credibility. Researcher bias and reflexivity have been accounted for in the presentation of the final interpretations of the emergent themes (Patton, 1990), as outlined in Section 8.2. Validity is essential if findings are to be used to influence practice (Long and Johnson, 2000). A service user day is planned to obtain feedback on the study findings and discuss ways the findings can be used in practice.

A personal reflexive account enhances the validity of study finding by ensuring transparency in relation to how the researcher's biases influenced; the developing relationship with participants; and data analysis and interpretation of findings (Northway, 2013). Researcher influences are unavoidable within qualitative research but a reflexive approach was employed throughout the study, particularly when undertaking the in-depth interviews with the children and parents; and when interpreting the data. As outlined in Chapter 4, Section 4.8.2, it was challenging in the initial phases of data analysis to use a qualitative researcher

lens and not a nursing lens. Ongoing critical reflexivity within research supervision meetings ensured assumptions were challenged during data analysis and generation of final themes.

Additional strategies employed to enhance the validity of the study included experienced researchers coding the data and interpreting the findings (Hafetz and Miller, 2010). This was achieved by both supervisors independently coding over half of participant transcripts to develop the coding index with differences debated until an agreement was reached. Equally important was demonstrating transparency of the data coding and interpretations of the findings. A range of data extracts across participants were used to highlight the range of both child and parent accounts and assist in demonstrating the transparency of the data findings and facilitate readers to make judgements about the relationship between participants' accounts and researcher interpretations. A record of each stage of the research process including the development of interview guides, detailed explanation of how data was generated and analysed and decisions about coding and negotiation with supervisor ensured a clear audit trail was maintained.

### **8.1.2 Reliability**

Reliability relates to consistency in data collection and analytical processes (Long and Johnson, 2000). There are three aspects to ensuring reliability in qualitative research: stability (would similar responses be provided by the participant at a different time) consistency (are participant's responses consistent) and equivalence (would similar responses be obtained for a similar question within the same interview) (Brink, 1991).

To ensure the reliability of the study there was a clear audit trail provided ensuring interpretations of data were consistent and transparent (Sandelowski, 1993). However, auditability does not in itself, confirm credibility of the findings, which is dependent on the quality of the decisions made and whether other researchers would make comparable conclusions following similar decisions (Slevin, 2000; Sandelowski, 1993). An acknowledgment of biases in sampling have been addressed (Morse *et al.*, 2002). For example, participants from deprived areas, families from ethnic minority backgrounds and fathers may have added a further dimension to the study findings. Different accounts are presented from all the participants (Lewis and Ritchie, 2003), and during the data analysis

the researcher alongside her two academic supervisors ensured the labels attached to data were meaningful (Lewis and Ritchie, 2003).

### **8.1.3 *Transferability of findings***

The transferability of findings within this study may be relevant for understanding similar processes in other contexts for other long-term childhood conditions (Holloway, 2005; Lincoln and Guba, 1985). Transferability has three interlinked elements: representational, inferential and theoretical transferability (Lewis and Ritchie, 2003). The first is concerned with representing the participant group and whether a different group of parents would result in similar findings (Lewis and Ritchie, 2003). In-depth data was obtained describing child and parent shared decision-making for asthma management with boys and girls, with differing severities of asthma, and found varying levels of agency across the seven to eleven age range. In addition parents with differing parenting styles offered detailed perspectives on management decisions operationalised within their family. The study findings are important to understand how children and parents shared asthma management decisions. Recruiting families from ethnic minority backgrounds, deprived areas or the father's perspective may have added another dimension to the findings. Inferential transferability relates to the application of findings to other contexts (Lewis and Ritchie, 2003). It is anticipated the questions within the interview guide are able to be applied to the management of other long-term conditions. Theoretical transferability relates to the wider implications of the study findings which could include influencing policy, contributing to existing theories and developing research methods (Lewis and Ritchie, 2003). The findings of this study highlight although policy guidance advocate a child's 'voice' is important in health matters that concern them, this is not happening in practice, especially within the school setting. The conceptual framework 'child-parent shared decision-making for asthma management' recognises the shared decision-making between the child and parent as a shifting process not a fixed linear from parent transition to child control (page 173).

## 8.2 Reflexivity

Reflexivity is linked to the quality and credibility of qualitative research and enables the researcher to account for her relationship with the participants and how they responded, to examine her assumptions and interpretations of the study findings (Clancy, 2013). Initially, it was challenging to co-construct the child and parent data through a researcher lens not a nursing lens, to focus primarily on the decision-making process for the asthma management and not the asthma condition. During the embryonic stage of this PhD study I was looking at child-parent shared decision-making rather naively and my assumptions were challenged by my supervisors within regular supervision meetings and email correspondence. My experiential knowledge and evidence based practice working as a school nurse and liaising with children within the school setting was dissimilar to liaising with children within a clinic setting, proceeded by in-depth interviews within the home environment. Within the school setting teachers were usually the main gatekeeper for access to the child, written consent was provided by the parent and assent from the child. As a school nurse my role was to conduct child health medicals with the school paediatrician, often eliciting sensitive medical history for inclusion within the school health records. I notified the parent usually via telephone or post that I was visiting the school to either: conduct a medical interview; update their child's medical care plan; or teach health related subjects to pupils and/or school staff, offering the parent the opportunity to attend. Only a small percentage of parents did not attend the medical but usually provided their consent for the child medical to be conducted in their absence. Therefore it was surprising that on average, 170 children missed their review appointments each month, within the clinic outpatient department.

Following careful planning of time, developing learning resources organisation of my own case load and preparation of the teaching session my previous experience in an attempt to educate school staff members on caring for a child with breathing difficulties, resulted in only four members of staff attending the rolling 15 minute training session arranged over four hours. As a qualified teacher I am fully aware of the demands of the workload on a teacher and the macro organisational rules within an education setting. Therefore I pre-arranged, with the senior management team, to be situated within the school staff room for

four hours. I was frustrated at the low uptake of an essential training session helping to support teachers to meet the health care needs of their pupils.

### **8.3 Reflection**

Reflection is the process of evaluating whether the research methods undertaken were appropriate to meet the study aims and given the opportunity what changes would be made if the study was repeated or a similar study was undertaken (Clancy, 2013; Hand, 2007; Carolan, 2003). If this study was to be repeated, additional strategies to improve recruitment would be adopted such as approaching children, albeit working with ethical principles, in the school setting about the study. Children, with parental assent would also be offered opportunity to undertake the interview at school, as this may facilitate the child to participate without the constraints of their parent as the gatekeeper to participating within the study and sits well with the notion of 'children as agents'. In addition, on average 170 children a month did not attend their outpatient review within the paediatric clinic; this group of children may have had differing views about participating in decisions about managing their asthma than those recruited from the clinic. Recruiting children within a school may also increase the likelihood of a heterogeneous sample in terms of socioeconomic status and encapsulate the local deprived area within which the first study was undertaken, reducing the constraints of parents as gatekeepers. Undertaking the study within the school setting may encourage, without coercion, inclusivity within the research study, facilitating collaborative working between child, parent, school staff and health care professionals to meet the health needs of a child with asthma. Securing funding to be able to utilise the services of an interpreter may have resulted in recruiting children from minority ethnic groups representative of the study population.

I presented a friendly, approachable and professional demeanour and identified children and parents responded well to this approach. For example, I received a frantic telephone call from one of the parents claiming she was unorganised and wanted reminding of the date of the interviews. Another parent arranged an interview for Christmas Eve, both her and her daughter were eager to participate. On arrival at the home the child was very keen to show me her Christmas tree and her family pets subsequently the interview was very relaxed

where the child eagerly articulated her responses to the semi-structured questions. Another child had baked some cakes in anticipation of my arrival and was talking animatedly from the outset as she waved from her window as I arrived. I felt I was very welcome within all the homes and perceive my friendly, bubbly disposition nurtured through my role as a mother of four children and school nurse role assisted in building and maintaining a participant-researcher relationship to obtain true responses from the child and parent within a naturalistic environment.

The methodology and methods employed within this study enabled the study aims to be achieved. The individual interviews enabled inclusion of a child within the seven to eleven year age range to participate within research about their own health. This study has acknowledged and facilitated child agency within the research of children. The research was conducted *with* the child not *on* the child, placing equal importance on their perspectives as that of their parents. The children enjoyed the drawing activity and what I anticipated would be a quick introductory drawing activity, often resulted in a natural dialogue to develop between myself and the child. The children appeared to enjoy discussing their drawings. Child participatory techniques, especially drawing, are a popular method to elicit data from children and in the case of this study were very effective in building a relationship and rapport with the child (Hortsman *et al.*, 2008). A drawing activity is familiar to children of all ages promoting a naturalistic environment. The children were also interested in the audio recording of their interview and wanted to listen to their own recorded voice prior to the in-depth interview questions commencing. Extra time would be allowed for this activity and to continue to build on the existing relationship, in future research within this topic area.

The semi-structured nature of the interview enabled me to obtain responses that answered the aims and objectives of the study, whilst also enabling participant's opportunity to discuss other aspects of the asthma management. In-depth interviews enabled individual perspectives on child-parent shared decision-making. Undertaking the interviews within the home provided a naturalistic environment alleviating the power relations especially between child and researcher. As the interviews progressed and I became immersed within the data, the focus of my attention altered, shifting towards incorporating the theory of new sociology of childhood (Corsaro, 2005; Mayall, 2002; James *et al.*, 1998) and capturing the child's

voice, which have not been widely represented in the research studies presented in Chapter 3. I particularly wanted to focus and work *with* the child, to encapsulate the child's perspective of child-parent shared decision-making for the management of asthma and not to conduct research *on* children.

As the study progressed and evolved, data collection and analysis methods were adapted. The child and parent interview guides enabled 'rich data' to be obtained. The systematic application of the framework approach enabled a clear audit trail of the development of the findings to be maintained, enabling transparency of interpretations of the data. Although, data is removed from the transcripts, data charting enabled the extracted data to be kept in context. The framework approach also facilitated a flexible, iterative approach to data analysis enabling data collection and analysis to occur simultaneously (Scrivasta and Thomson, 2009). Although data saturation was intended to be used, the sample size was self-limiting because a further extension from the Site Specific Research and Development would have been required and time constraints prevented this. Following regular supervision meetings, exploration of the literature and after I became immersed within the data, I realised the focus of the study was to listen to the child's voice and their perspective on the level of decision-making, which had sometimes been overpowered by the parent's perspective in previous research presented in Chapter 3.

#### **8.4 Study strengths**

Strengths of the study include: listening to the 'voice' of the child; addressing the gap in knowledge of shared decision-making for asthma management and differences in preferences for making decisions between the child and parent are reconsolidated; the study design embed the child's voice throughout the data collection, analysis and reporting of findings, enabling an accurate representation of both child and parent. To encapsulate the child's voice and ensure the parent findings did not dominate required careful consideration of the design of the study. The findings from this study add to understanding how the voice for the child in the shared decision-making for asthma management is enacted. One of the underpinning principles of this study was to accurately represent child and parent

perspectives in a way that was meaningful and demonstrated transparency of data analysis promoting credibility of the findings. This study also addresses the gap in knowledge of the intermediary stage where decisions for asthma management are shared between the child and parent; specifically focusing on any areas of friction or contentious decisions and how the child and parent work through these scenarios.

Middle childhood, aged range seven to eleven years respond well with either interviews or a focus group method of data collection (Fraser *et al.*, 2007). Individual in-depth interviews as a data collection method facilitated engaging with children as research participants and enabled their willingness to share their asthma management decision experiences. The range of child extracts presented within Chapters 5 and 6 highlight the child's willingness to elicit their responses to the interview guide within my research study. The children from the lower and upper age range (seven and eleven years) overtly discussed their participation within the shared decision-making for their asthma management. I drew on my wealth of experience and skills from a school nursing role, with over eight years working with children and their families and as a mother of four children, to effectively engage with the children and their families. I was familiar to the child and parent due to the former meeting within clinic and subsequent correspondence. This familiarity facilitated rapport building by actively drawing on information gained in the previous encounter in order to positively reinforce the value placed on participant's contribution to the research. Developing an interactive relationship with the child was facilitated through playing with the child prior to the interview (Kortessluoma *et al.*, 2003). However, using child participatory techniques such as a drawing exercise recognises the child as social actors in their own right and facilitated the active participation of the child (Christensen and James, 2008; Mayall, 2002). The innovative methods of data collection, such as drawing, have been used to increase effective child-researcher rapport (Carter and Ford, 2013), often used in health research settings with young children under twelve years of age (Kennedy *et al.*, 2001; Pridmore and Bendelow, 1995; Williams *et al.*, 1989) and proved to be effective within this study.

Careful consideration of previous research studies (Chapter 3) undertaken with children influenced the design of the study. The study setting was important to ensure a natural environment was available for the child to promote their true feelings, attitudes and beliefs



on asthma management decisions were captured (Lincoln and Guba, 1985). Therefore the interviews were undertaken within the natural environment of the children and their parents, in this case their home, minimising distress and reducing the child-researcher power balance (Greig and Taylor, 2005). Children with asthma attend regular reviews at the hospital and an acute asthma episode may hinder their school attendance therefore evening appointments were offered to minimise disruption to the child and parent by taking unnecessary time away from school and work, respectively. Separate interviews were important because the parent, in a position of power within the relationship, could potentially dominate when responding to questions and there was a danger the child's voice would not be heard (Mauthner, 1997). The interviews were undertaken in a safe environment with the parent available within an adjoining room. Individual interviews enabled a child art-based approach to be used with the aim of fostering a rapport to be established between the child and the researcher (Pridmore and Landsdown, 1997). Prior to commencing each interview, time was allowed for general introductions and confirming participants understood the purpose of the interview and other areas of concern when conducting research with children such as confidentiality. Within the individual interviews the child and parent were asked similar age appropriate questions on how they made decisions for the management of the asthma, enabling similarities and differences of the child and parent perspectives to be identified. In addition to drawing on personal professional experiences as a school nurse working with children and parents in primary health care settings, school and the family home, a range of probing techniques were used to enhance the quality of the data elicited.

Transcribing data verbatim enabled the analysis to remain close and true to the participant's own words, (Sandelowski, 2000), increasing the credibility of the research findings (Speziale and Carpenter, 2005). To capture the diversity of participant perspectives a range of quotes are presented in Chapters 5 and 6 (Spencer *et al.*, 2003). A particular strength of the framework approach is to enable transparency between the participant perspectives and the researcher interpretations (Morse and Richards, 2002), promoting the credibility of the findings to the reader.

## 8.5 Limitations of the study

Limitations of the study include: difficulty in recruiting children and parents; the sample not being representative of ethnically diverse population; fathers were under-represented within this topic. Lancashire, the location for this study, has been identified as an area of deprivation with many children identified as being in poverty (North West Public Health Observatory, NWPHO, 2009). It was anticipated that recruiting within the asthma clinic in East Lancashire would capture participants from the lower socio-economic families. However, the children and parents that participated within the study were not representative of the local area. Although, 'rich data' has been captured within this qualitative descriptive study, 170 children a month typically do not attend their outpatient appointment for their health needs. As many children rely on their parents taking them to the hospital, a different setting, such as a school may have recruited more children and parents especially from the lower socio-economic families. Parents may not be paid when they have to take time off work to attend the reviews and may provide a reason for their non-attendance, whereas a child is already present in school. My previous experience as a school nurse obtaining consent from children and parents for health interviews had been more successful within the school setting. Therefore, if this study was to be repeated I would recruit within the school setting. In addition I would seek funding to employ the services of a translator in an attempt to alleviate some of the recruitment problems in relation to ethnic minority communities.

The setting for this study also has an ethnically diverse population, black and ethnic minority groups are estimated to be 12%, with the predominant race being Pakistani (South East Public Health Authority, 2010). As Pakistani groups are the highest ethnic group reporting their health 'is not good' (Public Health England, 2013), recruitment from participants within this minority ethnic group was important. However, this study has not captured participants from the ethnic minority participants and may be attributed to one of the exclusion criteria stating participants must be able to speak and write the English language. When asked by the nursing staff children from ethnic minorities and their parents did initially demonstrate interest in participating. However, when they were introduced to me within the clinic area, it became apparent many of the parents did not speak English and could not be included

within the study. Employing an interpreter for future studies would promote inclusivity within this population.

Many children were accompanied by both their mothers and fathers to the asthma reviews. Fathers are under-represented within this topic area so it was hoped they would participate. However, apart from one father, only the mothers expressed interest in participating within the study. One father from an ethnic minority background was keen to participate, unfortunately his daughter refused. Children are active agents and competent to make decisions that affect them (Skanfors, 2009), so her wishes were respected. In hindsight this was a lost opportunity and the father could have been interviewed but this would have compromised listening to the child's voice which was an underpinning philosophy of the study.

## **8.6 Summary**

This chapter had highlighted the theoretical positioning of the researcher explaining how and why a qualitative descriptive design was used to ensure the aims and objectives of this study were achieved. The personal biases of the researcher and how they may have impacted on the study are clearly described within the reflexivity section. The design of the study employing the use of individual in-depth interviews and drawing activity (Appendix 18) for the children, conducted in a naturalistic environment, facilitated reliable and valid data to be elicited from child and parent to address the paucity of research within this topic area. Framework approach underpinned the findings and provided a systematic, iterative process of data analysis through interconnected stages enabling a clear audit trail and transparency of the researcher interpretations to the reader. Issues of rigour have been identified and critically discussed to demonstrate the credibility of the study findings and the application of the conceptual framework in the management of other long-term conditions. The particular strengths of this exciting study have been discussed and the limitations acknowledged with a reflective section highlighting how future studies could address these limitations.

**9. Introduction**

The work presented in this thesis has focused on child-parent shared decision-making for the management of childhood asthma. The empirical study that explored the child-parent shared decision-making processes contributes to the paucity of research in the area. This chapter summarises the key findings from: the critical evaluation of the theoretical perspectives that underpinned this thesis, which were used to help explain child-parent decision-making (Chapter 2); the review of published research that explored child-parent shared decision-making in the context of long-term conditions in children (Chapter 3); the study undertaken as part of this thesis (Chapters 4,5,6,7,8). In addition, the implications from the study findings in relation to policy, education and practice and future research directions are outlined. Finally, the publication and presentation dissemination strategy is presented.

**9.1 Summary of key findings**

There are several key messages that emerged from the work presented in this thesis. First, children seven to eleven years of age can make complex decisions about the management of their asthma. Empowering children to self-manage and make decisions about their health condition has the potential to improve health outcomes because children are more likely to respond and act on illness symptoms, more effective use of medicines and treatments, greater understanding of the implications of professional advice and improved ability to cope with the condition (DH, 2011; Coulter *et al*, 2008; DH, 2007). Health care professionals working with children and young people should seek children's opinions about the level they wish to be involved in the management of their condition and involve them as appropriate.

Second, although children have the capacity to make decisions about the management of their asthma, many children want to share decisions with parents. Health care professionals

have a role in empowering, without coercing, the child to be able to develop confidence to managing their condition and contribute along with their parent towards care decisions. Understanding the way decision-making operates with the family, should help health care professionals support parents in relation to the '*shifting and shared*' decision-making process that operate within the family.

Third, the shifting responsibility for asthma management decisions from parent to child, in response to the child gaining knowledge and experience of managing their condition, is not a linear process. In many instances managing asthma decisions is a shared process, with the interplay between child or parent in relation to who dominates decisions unique between and within families. The revised conceptual framework (page 175) illustrates how shared and sharing decision responsibilities is a dynamic and shifting process in response to family dynamics and in differing contexts both within and outside the family. It is essential the health care professionals understand the family dynamics and establish child and parent decision preferences in order to work effectively alongside the family to guide and support timely asthma management advice.

The revised conceptual framework will be presented at a User Service Day, in the asthma clinic where the study was undertaken. The purpose is two-fold: to present the findings, obtain feedback from the parents and children who participated in the study and the health care professionals who have supported the study and work with children with asthma; and to confirm a conceptual model that can be applied to professional practice to support both child-parent decision-making in asthma and health care professionals working with the child and family.

Understanding child-parent shared decision-making from the perspective of children and parents will help professionals support families to facilitate the child to become more involved in care decisions. There appears to be a paucity of research about child-professional and child-parent decision-making. The study undertaken as part of this PhD is novel; no other study has been identified that elicits data from child and parent participants and has explored the shifting and shared decision-making process of asthma management. Although Buford's (2004) research resulted in the development of a model for the 'transfer of asthma management responsibility from parent to their school-aged child', the child's

voice was not evident in the study findings or the development of the model. The strength of the study presented in this thesis includes embedding the child's 'voice' within the study findings and the development of the conceptual framework. In addition, the findings highlight that rather than the transfer of asthma management responsibility being a fixed linear transition (Buford 2004), child-parent decision-making for asthma management is a 'shifting and shared process'.

Fourth, findings from this study endorses recommendations that the education system should support the child and family, when a child has a long-term condition (Royal College of Nursing (RCN) and UNISON, 2012). Clear policies and guidance, centred round the child's needs and improved training for teachers and school support staff could ensure greater collaboration between health care professionals, particularly school nurses. Within the school setting, policies and procedures often disempower a child to self-manage their long-term condition (Garnett, 2013). Control of the decision-making is often in the domain of school staff, for example when a child is unable to retain responsibility for their inhalers (Walker, 2013). Yet, evidence suggests that about a third of teachers lack confidence in administering medication to children with long-term conditions (Walker, 2013; Sandsund, 2011; Bruzzese *et al.*, 2010).

Finally, within the family system, parents may enable or hinder the agency of a child in relation to participating in decision-making for their asthma management. Parenting styles can impact on 'thickening' a child's agency and promote the child's independent thinking whilst still maintaining some control of the decision; or 'thinning' a child's agency by enforcing, without reasoning, management decisions (Santrock, 2007). A parent may demonstrate submissiveness or dominance within the decision-making process, ignoring or not listening to their child's decision preferences. There is a need for further research within this area specifically focusing on system level barriers of child collaboration within participation of asthma management decision-making, to reduce the barriers and acknowledge and promote how children can be independent and autonomous to coincide with child and parent decision preferences.

## 9.2 Implications for practice

The implications from the study findings relate to policy, education and practice. First, health policy should take into account the child's ability to contribute to decisions about their care and care management plans in relation to their long-term condition. Autonomy is given to the child in-line with their competence not chronological age, as adults are likely to underestimate the child's capability of decision-making when following the guidelines of child development theories or models (Buford, 2004; Smith, 2002; Mayall, 2000; Piaget, 1969).

Second, embracing the 'Expert Patient Programme' (DH, 2001) and educating the child, parent and school staff in effective management decisions of the child's asthma will facilitate the child enjoying the same daily activities as their peers. Support and guidance from the health care professionals in including the child within the management decisions of their asthma will promote optimum health behaviour management of their asthma reducing emergency admissions and consequently expenditure on the National Health Service. The safe effective collaborative working will ensure overt decision-making is established and maintained.

Third, for teachers and school staff to develop the skills to meet the health needs of children requires specific training for each child (Garnett, 2013; Walker, 2013). Individual health care plans are essential to facilitate this support (Walker, 2013). School nurses are ideally placed to work collaboratively with children, parents, education and other health care professionals in promoting the health care needs of a child with asthma. The recent decision not to provide this essential service with extra funding needs to be revisited and reviewed (Blakemore, 2013). More school nurses and children community nurses are required to provide the education for children, parents and school staff to work collaboratively in meeting the child's health needs to ensure full inclusivity within school life (Walker, 2013; RCN and UNISON, 2012). UK government policies that promote the health and well-being of children (Healthy Weight, Healthy Lives, 2008; DCSF, 2007; DH, 2004) and the new sociology of childhood studies advocating children are involved in their own health decisions (Tisdall and Punch, 2012; Valentine, 2011; Corsora, 2005; Berthelson and Brownlee, 2005; Mayall *et*

*al.*, 2002), have poor implementation within the school setting as education staff do not always recognise children's autonomy and independence.

Finally, in relation to practice an awareness and understanding of the process of sharing and shared decision-making that occurs with families where a child has a long-term condition could be used by health care professionals when supporting the child and family to manage the child's long-term condition. Professionals need to influence and challenge policies, for example the school policies and procedures relating to managing a child with a long-term condition within the school are not necessarily operationalised. Evidence suggests less than 3% of children with asthma have an individual asthma care plan in school (Roberts and Campbell, 2013). It is essential every child with asthma has an up to date personal asthma action plan, reviewed regularly in collaboration with the child, parent, health care professional and school staff to ensure the plan is utilised effectively within the school setting, if the child's health and wellbeing is to be maximised. Systems and processes do not appear to be working, hindering collaboration across agencies and ultimately impacting on supporting the child to make decisions about managing their condition. Consequently, some children retain their inhalers in breach of school policies (Cashin *et al.*, 2008). This practice does not recognise the agency of the children and their role in managing their condition. A more overt and collaborative way of working with children, supporting them to manage their condition is required. A regular review of the individual personal asthma action plan within the school to meet the evolving needs of the child will assist in meeting these health care needs.

### **9.3 Future research directions**

Future research directions will further develop the findings of this novel study. First, being passionate about promoting children and young people's health and the concept of children's agency, future research with children (recruited from school without the constraints of their parent as the gatekeeper but working within ethical frameworks) could build on these findings by exploring strategies children perceive would support them to contribute to being involved in the management of their asthma. The ultimate aim would be



to develop and evaluate a training programme for children, parents and health care professionals focusing on the skills required to effectively involve children in the management of their asthma. Best practice for children deemed competent to have free access to their own asthma inhalers.

Second, asthma can have a significant impact on a child's health and well-being and for many children continues into adulthood. There is a gap in research relating to understanding how children and their parents share management decisions during the young person's transition to adulthood and the impact of developing effective decision-making skills in childhood influences the way asthma is managed in early adulthood.

Third, research could be undertaken with children to extend these exciting findings, investigating the level of agency further; specifically exploring when the child wants to demonstrate agency and when they choose not to exert agency. Exploring agency within different contexts may assist families, health care professionals and education staff to work collaboratively with the child, developing their confidence to make autonomous asthma management decisions.

Fourth, future research could explore asthma management differences in children that have and do not have an individual asthma care plan within school. The value and usefulness of an individual asthma care plan could guide future health and education policies and identify way to facilitate children with asthma to reach their maximum potential and enjoying a fulfilling life without asthma symptom restrictions.

## 9.4 Dissemination strategy

Publications and presentations dissemination strategy is presented in Table 14.

**Table 14: Dissemination strategy: present and future**

<b>Presentations:</b>
Garnett, V. E. (2012) Child-parent shared decision-making in asthma management. <i>Celebrating Research Day</i> , University of Salford.
Garnett, V. E. (2012) Child-parent shared decision-making in asthma management. <i>Celebrating Success: Children and Young People's Field of Practice Conference</i> , University of Salford.
Garnett, V. E. (2012) Children and Young People @ Salford (poster). <i>Research with Children, Young People and Families: Children and Young People's Field of Practice Conference</i> University of Salford.
Garnett, V. E. (2013) Child-parent shared decision-making for the management of asthma: <i>Manchester Research in Child Health Forum</i> , Royal Manchester Children's Hospital.
Garnett, V. E. (2013) Child-parent shared decision-making for the management of asthma in children: <i>Paediatric Nursing Association of Europe</i> , Glasgow.
Garnett, V. E. (2014) How children and their parents make decisions for asthma management: <i>United Kingdom Association of Chief Children's Nurses</i> , Jersey.
<b>Publications:</b>
Garnett, V. E. (2013) Communication is key to effective asthma management in school children. <i>Nursing Children and Young People</i> , <b>25</b> (1) 11.
<b>Future publications strategy:</b>
Child-parent shifting and shared decision-making for the management of asthma – a qualitative interview based study. <i>Issues in Comprehensive Pediatric Nursing</i> .
Structured literature review of child-parent shared decision-making for the management of a long-term condition. <i>Journal of Advanced Nursing</i> .
Methodological challenges of interviewing families – a worked example. <i>Nurse Researcher</i> .

Three articles have been identified as potential publications from the work undertaken within this thesis. The first article, in progress, will present the findings from the qualitative descriptive study of child-parent shifting and shared decision-making for the management of asthma. The second article will be a structured literature review of child-parent shared decision-making for the management of a long-term condition. The third article will focus on the methodological and practical challenges when researching with children and families.

## 9.5 Summary

In summary, the research presented in this thesis revealed that both children and parents want to share in making decisions about managing the child's asthma and perceive the child's developing autonomy in managing their condition will maximise the child's health and well-being. More specifically the child's self-efficacy belief and the parent's confidence in their child's ability to manage their own asthma decisions will ensure child and parent decision preferences are acknowledged and accommodated within the management care.

Further research exploring how children and parents manage decisions acknowledging and understanding the '*shifting and shared*' decision-making process that takes place within the family is warranted. This would extend the exciting findings within this novel study and further develop an understanding of how management decisions are not transferred from parent to child but are '*shifted and shared*', dependent on child and parent decision preferences and various contextual factors.

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### Appendix 1: Example of a search strategy

Medline database via OvidSP host system: January 2000 – April 2014		
Final update: 07/04/14		
Search terms		Results
1	Child.mp. or Child/	1499629
2	*Pediatrics/	27245
3	Daughter.mp.	12415
4	Son.mp.	12594
5	1 or 2 or 3 or 4	1532540
6	parent.mp. or *Parents/	109750
7	father.mp. or *Fathers/	19085
8	mother.mp. or *Mothers/	87079
9	carer.mp. or *Caregivers/	14262
10	guardian.mp.	1590
11	foster carer.mp.	8
12	grandparent.mp.	513
13	6 or 7 or 8 or 9 or 10 or 11 or 12	214750
14	Chronic Disease/ or long term illness.mp.	211823
15	Chronic illness.mp. or *Chronic Disease/	17375
16	Chronic Disease/ or chronic condition.mp.	212901
17	14 or 15 or 16	216759
18	decision-making.mp. or *Decision-making/	26311
19	partnership.mp.	12439
20	collaboration.mp.	31595
21	18 or 19 or 20	69075
22	5 and 13 and 17 and 21	40
23	Limit 22 to (English language and humans and yr="2000-Current")	30

## Appendix 2: Data extraction form

<b>Article Identification</b>			
<b>Author:</b>		<b>Title:</b>	
<b>Source:</b> Medline   CINAHL   PsycINFO   Web of Knowledge   Science Direct Hand Search   Other			
<b>Data Extraction</b>			
<b>Location:</b> UK USA Australia Canada Other:	<b>Participants:</b> Child Child and parents Both parents Mother Father Other	<b>Health conditions:</b> Range Single Condition	<b>Focus:</b> Decision-making Collaboration Partnership
<b>Quality of study</b>			
Theoretical foundations:			
<b>Study design:</b> Qualitative: Grounded theory Phenomenology Ethnography Generic Mixed method: Quantitative	<b>Sample strategy:</b> Purposeful Selective Convenience Not described Sample size:	<b>Data collection:</b> Questionnaire Interview Focus groups Other	<b>Data analysis:</b> Statistical Grounded theory Phenomenology Framework Content Analysis Thematic analysis Other
<b>Data Extraction and synthesis</b>			
Categories:			
<b>Additional Information</b>			

### Appendix 3: Assessment of the quality of the papers based on CASP tool

Author/s	CASP appraisal tool criteria for qualitative studies									
	Clear Aims	Methods appropriate	Appropriate recruitment	Appropriate data collection	Rigor of data analysis	Researcher influences considered	Clarity of the findings	Interpretations justified	Transferability	Relevance
Alderson et al (2006a)	✓	✓	✓	✓	X	X	✓	✓	✓	✓
Alderson et al (2006b)	✓	✓	✓	✓	X	X	✓	✓	✓	✓
Buford (2004)	✓	✓	✓	✓	P	X	✓	✓	✓	✓
Cashin et al (2008)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Fereday et al (2009)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Hafetz and Miller (2010)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Meah et al (2009)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Meng McConnell (2002)	✓	✓	✓	P	P	X	X	X	✓	✓

Miller et al (2008)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Miller (2009)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Newbould et al (2008)	✓	✓	✓	P	P	X	P	✓	✓	✓
Pradel et al (2001)	✓	✓	✓	P	✓	✓	✓	✓	✓	✓
Pritchard (2012)	✓	✓	✓	✓	✓	P	✓	✓	✓	✓
Taylor et al (2009)	✓	✓	✓	✓	✓	X	P	P	✓	✓
Williams et al (2007)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓

✓ yes criteria fully met

x no criteria were met

p criteria statements partially met

**Appendix 4: Quality assessment tool for quantitative studies (HCPREDU - adapted)**

<b>Author/s</b>	<b>Study overview</b>	<b>Study, setting, sample</b>	<b>Ethics</b>	<b>Group comparability and outcome measurement</b>	<b>Policy and practice implications</b>	<b>Number of references/Name of reviewer/date</b>
Chisholm <i>et al.</i> (2012)	✓	✓	X	✓	✓	✓
Miller and Harris (2012)	✓	✓	✓	✓	✓	✓
Kiechefer <i>et al.</i> (2009)	✓	✓	X	✓	✓	✓

✓ yes criteria fully met

x no criteria were met

## Appendix 5: Child participant information sheet



### Child Participant Information Sheet

**Project title:** Child-parent decision-making for the management of asthma.

**How you and your parent look after your asthma:**

Hello my name is Vicky and I am a student doing a project about children like you with asthma.

I would like to invite you to take part in my research study.

Ask me if you do not understand or would like more information about the study.

**What am I doing?** I am talking to about 10 children who have asthma and the people who look after them. I want to know more about how you take care of yourself and your asthma.

**Do I have to take part?** You do not have to take part if you do not want to, even if the person who cares for you agrees to take part. If you would like to take part, talk with the person who looks after you and if you both agree, I will arrange to visit your house at a time to suit. I hope to hear you share information and views about what it is like living with asthma. I will ask you to draw or write something about what asthma means to you.

**What if I am not sure about taking part?** Talk to the grown-up who is with you. You can say no if you do not want to. I will not mind.

**How long will it take?** It will take between 30 minutes and 40 minutes but you will be able to stop whenever you want and take a break. If you become upset during the interview, for any reason, then you will be asked if you would like to take a break and/or speak with the person who cares for you, in private. You may also be asked if you would like to do the interview another time, or to stop taking part.

**Will you tell anyone what I say?** No, what you say will be private unless you tell me anything about you or someone else being hurt or at risk of being harmed

**What will happen with what I tell you?** I will type reports about what everyone tells me.

**Will my name be used?** No, I will not use your name and I will do my best to make sure that no one will know it is you I am talking about.

**What if I want to do it?** I will ask you to write on a form saying you want to do it and on another day I will come and see you at your home. If you change your mind and think that you do not want to do it anymore then that is ok, just let me know. I won't mind.

If you have any questions please ask your parent or guardian to get in touch with me.

Vicky Garnett

PhD Research Student

[v.e.garnett@edu.salford.ac.uk](mailto:v.e.garnett@edu.salford.ac.uk)

School of Nursing & Midwifery

Mary Seacole Building (1.96)

University of Salford

Tel 07954695965.

Thank you for reading this



Vicky 😊

## Appendix 6: Parent/Guardian Participant Information Sheet



### Parent/Guardian Participant Information Sheet

**Project title:** Child-parent decision-making for the management of asthma

**Researchers:** Ms Vicky Garnett

**Contact:** Ms Vicky Garnett - email [v.e.garnett@edu.salford.ac.uk](mailto:v.e.garnett@edu.salford.ac.uk)

Supervisor: Dr J. Smith – 0161 2957132 or email [j.smith3@salford.ac.uk](mailto:j.smith3@salford.ac.uk)

Co-supervisor: Professor P. Ormandy – 0161 2950453 or email [p.ormandy@salford.ac.uk](mailto:p.ormandy@salford.ac.uk)

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part.

#### Background Information:

**What is the purpose of the study?** This study will form part of Ms Vicky Garnett's PhD. The purpose of the study is to gain an understanding about your family's preferred approach to decision-making about asthma. Ideally, we wish to seek both a parental viewpoint and also the child's perspective about the management of asthma within an interview.

**Why have I been invited?** You have been approached to take part within this study as we understand that you are a parent/guardian to a child aged between 7 years and 11 years, with a diagnosis of moderate to severe asthma. In total, there will be approximately 10 - 12 children and their parent/guardian participating within this study.

**What will happen to me if I decide to take part?** The interview will last for approximately 30- 60 minutes. Open ended questions will be asked to your child and yourself about your chosen approaches to asthma care for your child.

Ideally, we would like to talk with both parents. If your child has more than one carer and they also wish to be interviewed please inform me and I will arrange for their inclusion.

If you decide that you do not want to participate within this study it will not affect the standard of care your child receives within the hospital.

**Where will the interviews take place?** If you feel comfortable, you will be interviewed within your own home at a time to suit you and your family. Ideally, parents and children will be interviewed separately unless this would be a problem and you prefer to be interviewed together.



**What are the possible benefits of taking part?** Although you will not receive any direct benefits from participating, we hope that your participation may inform the future delivery of asthma management by health professionals and families.

**What are the possible risks of taking part?** It is envisaged that there will be no risk to either your child or yourself. However the researcher is aware that sensitive issues are being explored which may cause upset. Should you become distressed during the interview the interviewer will stop the recording and ask if you would like to take a break or reschedule the interview or withdraw from the study. Appropriate support services are available for you to access if further support is required. The details are provided within this form.

**What happens to the information collected?** The collection, storage and disposal of the data will be kept in accordance with the Data Protection Act (1998). An electronic copy of the data will be stored upon a password protected computer located at the University of Salford. To maintain confidentiality all participants will be allocated a study code that will be held on a password protected computer, accessed only by the researchers. You can be assured that information collected is confidential and only be available within the research team. The interview will be audio recorded, with your consent, again only the researcher and the two supervisors will have access. The audio recordings of the interview will be disposed of, in accordance with the Data Protection Act (1998), six to twelve months following the completion of the study.

Although outcomes may be reported in publications, reports or conferences please be assured that any quotations will be anonymised neither you or the hospital will be able to be identifiable. If there is a potential risk of harm identified the researcher will adhere to the University of Salford's 'Safeguarding Children and Vulnerable Adults Policy'.

If you have a concern about any aspect of this study, you should ask to speak to any of the researchers listed at the top of the page, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the University of Salford via Matthew Stephenson telephone 0161 295 3152 email [m.stephenson@salford.ac.uk](mailto:m.stephenson@salford.ac.uk) who will deal with your complaint according to the University complaints procedure. Patient Advice and Liaison Services, located at East Lancashire NHS Trust, may also be contacted on 01772 695300.

**If you have a query about asthma:** you can contact the Asthma UK Advice line team of asthma nurse specialists by telephone. Tel: 0800 121 62 44, Monday-Friday 9am-5pm.

<http://www.asthma.org.uk>

**Involvement of the General Practitioner/Family Doctor (GP):** Unless you request, your GP will not be informed of your participation within this study.

**Who has reviewed the study?** This study has undergone a rigorous process of national review and has been approved by the NRES Committee North West Liverpool East and the Ethical Committee at University of Salford. The Research and Development Department at the Royal Blackburn Hospital within East Lancashire NHS Trust have also reviewed and provided approval for this study.

**If I need independent advice about taking part who can I contact?**

Linda Gregson  
 Research and Development Office  
 Level 3  
 Royal Blackburn Hospital  
 Haslingden Road  
 Blackburn  
 BB2 3HH  
 Tel 01254 733008  
 Email: [Linda.Gregson@elht.nhs.uk](mailto:Linda.Gregson@elht.nhs.uk)

**The main researcher can be contacted as follows:**

Vicky Garnett  
 MSc, BSc (Hons), PGCE (PC), RGN  
 PhD Research Student  
 Graduate Teaching Assistantship  
[v.e.garnett@edu.salford.ac.uk](mailto:v.e.garnett@edu.salford.ac.uk)  
 School of Nursing & Midwifery  
 Mary Seacole Building (1.96)  
 University of Salford  
 Tel 07954695965.

## Appendix 7: Child consent form



## CHILD CONSENT FORM

Participant Identification Number:

**Title of Project: Child-parent decision-making for the management of asthma  
How you and your parent look after your asthma:**

Please read the following statements carefully and **initial each box if you agree:**

1. I have read (or Vicky has read to me) and understood the information sheet dated 7/12/11 (version 2) for the above study. Vicky has explained things that I did not understand. ☐
  2. I understand that it is my choice to talk to Vicky about my asthma. If I decide that I do not want to be involved anymore I need to tell Vicky or the person that looks after me. I will still be able to see the doctor about my asthma. ☐
  3. I understand that any information I provide may be looked at by responsible people relevant to my taking part in this research. I allow for these people to look through my asthma records. ☐
  4. I agree to what I say during the interview being recorded for the study. ☐
- OR**
5. I **DO NOT** agree to what I say being recorded for the study , but agree to it being written down. ☐
  6. I agree to take part in the study. ☐

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date Signature

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes.

## Appendix 8: Parent/Guardian consent form



## PARENT/GUARDIAN CONSENT FORM

Participant Identification Number:

**Title of Project: Child-parent decision-making for the management of asthma**

Please read the following statements carefully and **initial each box if you agree:**

1. I confirm that I have read and understood the information sheet dated 7/12/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
  2. I understand that my participation is voluntary. I may, any time, withdraw from the study without giving any reason and without it affecting my child's medical treatment. ☐
  3. I understand that information, including personal data, I provide may be looked at by responsible individuals relevant to my taking part in this research. I give permission for these individuals to have access to my child's medical records. ☐
  4. I agree to my discussion during the interview being audio recorded for transcription purposes ☐
- OR**
- I **DO NOT** agree to my discussion being audio recorded for transcription purposes, but agree to have written notes taken. ☐
5. I agree to responsible individuals, under the direction of the Chief Investigator, having access to the information I provide, in anonymised form, for the purposes of additional data analysis. ☐
  6. I agree that my child and I will take part in the study. ☐

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date      Signature

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date      Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

## Appendix 9: Demographics Form

### Personal Family Identifier Number

1. Female ☐ Male ☐

2. What is your relationship to the child \_\_\_\_\_

3. How would you describe your ethnic origin?

Asian or Asian British: Bangladeshi ☐ Mixed: White and Asian ☐

Asian or Asian British: Indian ☐ Mixed: White and Black African ☐

Asian or Asian British: Pakistani ☐ Mixed: White and Black Caribbean ☐

Asian or Asian British: Other ☐ Mixed: Other ☐

Black or Black British: African ☐ White British ☐

Black or Black British: Caribbean ☐ White: Irish ☐

Black or Black British: Other ☐ White: Other ☐

Chinese ☐ Other ethnic group ☐ Prefer not to say ☐

4. How would you describe your current employment situation?

Job seeker ☐

Fulltime carer ☐

In part-time employment ☐

In full-time employment ☐

Voluntary work ☐

Other, *please specify* \_\_\_\_\_

5. Title of your current or most recent employment

6. Your child's date of birth

7. Child's gender Female ☐ Male ☐

8. Approximate date of the diagnosis of asthma

If you would wish to receive a copy of a summary of the research findings, please provide your address:

---

## Appendix 10: Child Interview Guide

### Guiding questions

Descriptive

#### So to start off.....

Would you tell me about your family? (Prompts- do you have any brothers or sisters? What are they called? How old are they? How old are you? What do you like to do? )

#### I am now going to ask you some questions about your asthma.....

Can you tell me how long you have had asthma?

What are the early warning signs that your asthma is starting up? (Prompts-So what do you do then?)

Can you describe anything that makes your asthma worse?

Do you avoid these things that make your asthma worse?

#### Making decisions about the asthma management.....

Do your parents involve you in decisions about your asthma treatment? (Prompts- what age was you when your parents started to involve you in the decision-making? What decisions were you involved in?)-

What decisions would you like to be involved with?

How do you and your parent make the decision to avoid things that make your asthma worse?

How do you decide if you need your parent to help you manage your asthma?

Are there any times when you have disagreed about taking your asthma medication? (SDM process)

Do you always remember to take your medication? Has there ever been a time when you have forgotten? What happened? (Barriers and facilitators).

How do you feel about taking inhalers? (Prompts- do you need anyone to check you are taking your medicines properly? Does it depend on where you are eg school, home, sleep-over. Do you initiate the use of inhaler?)-

How do you know if you are taking your asthma medicine properly?

What helps and what causes a problem between the decision-making process?)

What are the benefits of decision-making?

When you go to the doctors (hospital) do you get chance to talk to the doctor and nurses about your asthma? What do you tell them? (Prompts- how do you and your parent decide if/when to seek health care advice and support?).

#### I want you to think back to the last time you found it really hard to breathe....

Think back to the last time when you had an asthma attack when your parent was there, what happened? Can you tell me how you were feeling?

Think back to the last time you had an asthma attack when your parent was not there, what happened? Can you tell me how you were feeling?

#### We are nearing the end of the interview.....

What would you tell a friend if they had asthma and were worried about having asthma or discussing the management of the asthma with their parent?

Do you have anything you wish to add?

Emotion



## Appendix 11: Parent Interview Guide

### Guiding questions

Descriptive

#### So to start off.....

Would you tell me about your child? (Prompts- does he/she have any brothers or sisters? What are they called? How old are they? How old is your child? What does your child like to do? )

#### I am now going to ask you some questions about your child's asthma.....

Can you tell me when your child's asthma was diagnosed?

What are the early warning signs that your child's asthma is starting up? Can you describe anything that makes your child's asthma worse?

Does your child avoid these things that make their asthma worse?

#### Making decisions about the asthma management.....

Do you involve your child in decisions about their asthma? (Prompts- what age was your child when you started to involve them in the decision-making? What decisions were they involved in?)

What decisions would you like your child to be involved with?

How do you and your child make the decision to avoid things that make their asthma worse?

How do you decide to let your child make asthma management decisions and how do you decide to make the decisions?

Are there any times when you have disagreed about them taking their asthma medication?

Does your child remember to take their medication? Has there ever been a time when they have forgotten? What happened? (Prompts- do they need anyone to check they are taking their medicines properly? Does it depend on where they are eg school, home, sleep-over)

How do you know if your child is taking their asthma medicine properly?

What helps and what causes a problem between the SDM process?)

What are the benefits of SDM?

When you go to the doctors (hospital) does your child get the chance to talk to the doctor and nurses about their asthma? What do they tell them?

#### I want you to think back to the last time your child found it really hard to breathe....

Think back to the last time when your child had an asthma attack when you were there, what happened? Can you tell me how you were feeling/what you did?

Think back to the last time you had an asthma attack when you was not there, what happened? Can you tell me how you felt?

#### We are nearing the end of the interview.....

Do you have anything you wish to add?

Emotion



## Appendix 12: Example of the child coding matrix

Participants	Description (in-vivo codes)	Preliminary thoughts (what this is about)	Initial Categories
<b>Interview Transcript</b> <b>Family 3 Dean 7 years</b> <p>I had asthma before I started school. I remember because I <b>had my inhaler in school</b>. It was kept in a <b>box</b> in class where all the medical stuff is kept. <b>If I needed my inhaler we would ask Miss</b> and go and get it. I would go and get it.</p> <p>Early warning <b>signs are wheezing</b>. If my <b>chest is beating really fast</b>. Sometimes I <b>get a stitch in my heart</b> and then I need to go in and get my inhaler</p>	<p><b>I had my inhaler in school... in a box</b></p> <p><b>if needed my inhaler we (<i>Dean and friend</i>) would ask Miss</b></p> <p><b>signs are wheezing... chest is beating really fast</b></p> <p><b>I get a stitch in my heart and then I need to go in and get my inhaler</b></p>	<p>Inhaler at school - dependent on teacher to access inhaler</p> <p>Know when to ask for inhaler</p> <p>Know signs of asthma</p> <p>Know when to get inhaler</p>	<p>Dependent on others to access inhaler</p> <p>Deciding independently when to use inhaler</p> <p>Recognising signs of asthma</p> <p>Deciding independently when to use inhaler</p>



## Appendix 13: Example of the parent coding matrix

Participants	Description (in-vivo codes)	Preliminary thoughts (what this is about)	Initial Categories
Interview Transcript Family 3 Jenny, mother to Dean 7 years			
The early warning signs are you can hear it. <b>You can hear the wheeze he starts coughing and actually now he is older he will come and say my chest feels tight.</b>	<b>You can hear the wheeze he starts coughing and actually now he is older he will come and say my chest feels tight</b>	Child can understand about his asthma symptoms	Confidence in child's ability to understand his asthma symptoms
<b>I would say from being 3, 4 or 5 we would say to him if he started coughing we would say does your chest feel tight</b> do you need your magic puffer and he would say yes or no... unless I have felt... <b>mm... this is more... because there have been times when we have had to take him to hospital...</b>	<b>I would say from being 3, 4 or 5 we would say to him if he started coughing we would say does your chest feel tight</b>  <b>mm... this is more...because there have been times when we have had to take him to hospital</b>	Encouraged child to express a view regarding the decision-making for asthma management  Child usually involved in the decision unless symptoms are more severe	Understanding asthma symptoms  Parent dominates decisions if symptoms severe

## Appendix 14: Coding Index - Child

Initial categories	Initial themes
1.1 Modifying behaviours because of asthma symptoms	1.Understanding asthma and management
1.2 Differentiate between treatments due to colour of inhaler	
1.3 Recognise inhaler use relieves symptoms	
1.4 Recognising different levels of breathlessness	
1.5 Understanding asthma and the treatment	
1.6 Recognising signs of asthma	
1.7 Recognising general triggers	
1.8 Aware of how to reduce risk of symptoms	
1.9 Recognising specific triggers of asthma	
2.1 Making independent decision to continue activity in presence of asthma symptoms	2.Independent decision-making
2.2 Independently acknowledging association between symptoms and treatment	
2.3 Making decision about modifying behaviours because of asthma symptoms	
2.4 Independent decision of when to use inhaler at home	
2.5 Making independent decision to resume activity following asthma symptoms	
2.6 Deciding independently when to use inhaler at school	
2.7 Asthma triggers do not prevent activities	
3.1 Share the decision for asthma management	3.Sharing decision-making
3.2 Prompts by parent for treatment decision	
3.3 Sharing decision to go to the hospital	
3.4 Sharing decisions help child to manage inhaler use	
3.5 Involving mum in the treatment administration	
3.6 Asking mum for help when communicating with health care professionals	
3.7 Involving mum in the treatment decision	
3.8 Sharing decisions facilitates self-management	
3.9 Shared decision to go home when symptoms persist	
3.10 Share decisions when to resume physical activity	
3.11 The child requires help to make the right decision	
4.1 Child gaining control of asthma treatment due to colour of inhaler	4.Facilitators and barriers for decision-making
4.2 Independently use inhaler due to ready access	

<b>4.3</b> Dependent on others to access inhaler	
<b>4.4</b> Inform parent of child's management for asthma condition	
<b>4.5</b> Independently use inhaler due to ready access	
<b>4.6</b> Child is confident in their own asthma management	
<b>4.7</b> Parental absence facilitates own decision-making	
<b>5.1</b> Shifting responsibility back to parent when symptoms severe	5. Parent dominates care decision
<b>5.2</b> Shifting responsibility back to parent in presence of additional illness	
<b>5.3</b> Parent dominates the decision if symptoms persist	
<b>5.4</b> Parent tells the child to take inhaler	
<b>5.5</b> Parent informs the child how many puffs of inhaled medication to administer	
<b>5.6</b> Parent informs the child when activity can resume	

## Appendix 15: Parent Coding Index

Initial categories	Initial themes
<b>1.1</b> Child does not avoid specific triggers <b>1.2</b> Child is in control of day-to-day management <b>1.3</b> Asthma does not stop child doing anything <b>1.4</b> Teaching the child to listen to their own body <b>1.5</b> Child recognising illness symptoms relate to asthma <b>1.6</b> Parent encourage self-management <b>1.7</b> Illness symptoms and treatment <b>1.8</b> Child can differentiate between treatments	<b>1. Parents believes in their child's ability to make decision</b>
<b>2.1</b> Child will alert parents in presence of symptoms <b>2.2</b> Parent supports the child in their decision <b>2.3</b> Parent encourages child to liaise with the HCP <b>2.4</b> Parent gives away the decision but monitors behaviour <b>2.5</b> Parent aware child does not always administer preventative <b>2.6</b> Involving the child from a young age	
<b>3.1</b> Parent is confident in child's ability to self-manage <b>3.2</b> Child's access to inhaler <b>3.3</b> Parent prompts preventative treatment <b>3.4</b> Parent available if required <b>3.5</b> Daily routine encourages self-management <b>3.6</b> Additional medical diagnosis <b>3.7</b> Adding to developing life skills	<b>3. Facilitators and barriers of child's self-management</b>
<b>4.1</b> Alternative remedies <b>4.2</b> Parent decides when child is absent from school <b>4.3</b> Parent would decide to take child to hospital <b>4.4</b> Mum will make sure child takes inhaler if she has concerns <b>4.5</b> Parent omits some of child's medication with the doctor's consent <b>4.6</b> Parent observes for nocturnal symptoms <b>4.7</b> Parent would take over in a bad asthma attack	<b>4. Parent dominates care decisions</b>

### Appendix 16: The development of core concepts and themes - child

Initial themes	Refined categories	Links between categories	Final themes	Core concepts
<b>1. Understanding asthma and management</b>	1.1 Reaction to asthma symptoms 1.2 Understanding treatment due to colour of inhaler 1.3 Response to specific triggers	1.1 Developing autonomy (2) 1.2 Gaining control (3.1) 1.3 Developing asthma management experience (2)	- Understanding asthma and treatment - Recognising and responding to asthma symptoms - Recognising and responding to asthma triggers	<b>MAKING SENSE OF ASTHMA</b>
<b>2. Independent decisions</b>	2.1 When to use inhaler 2.2 When to modify behaviour in presence of asthma symptoms	<u>Decision-making is threaded throughout all initial themes</u>	- Transition of management decisions from parent to child - Requires support to manage asthma - Defers care decisions to parent - Parent dominates care decisions	<b><u>CHILD DECISION PREFERENCES</u></b>
<b>3. Sharing decisions</b>	3.1 Sharing the decision for asthma management with parent/adult 3.2 Asking parent/adult for assistance with management decision 3.3 Prompts by parent for treatment			
<b>5. Parent dominates the decision</b>	5.1 Shifts the decision back to the parent 5.2 Parent decides when to seek medical assistance 5.3 Symptoms severe 5.4 Additional acute illness 5.5 Treatment decision			
<b>4. Facilitators and barriers for own decision-</b>	4.1 Dependent on others to access inhaler 4.2 Locus of control	4.1 Knowledge and experience (1 & 2) 4.2 Level of	- Accessibility of inhaler - Confidence in self-management	<b>FACILITATORS AND BARRIERS</b>

<b>making</b>	4.3 Self-efficacy belief 4.4 Availability of inhaler 4.5 Parental absence facilitates autonomy	autonomy (5)	of asthma - Influence of Parent/adults	<b>OF CHILD'S SELF-MANAGEMENT</b>
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### Appendix 17: The development of core concepts and themes – parent

Initial themes	Refined categories	Links between categories	Final themes	Core concepts
<b>1. Child is developing skills to make decisions about asthma</b>	1.1 Child responsibility for daily asthma management 1.2 Child has some responsibility for treatment decisions 1.3 Child behaviour to specific triggers	1.1 and 1.2 link to making sense of asthma management decisions (2)	- Teaching child to listen to own body - Recognising and responding to asthma symptoms - Recognising and responding to asthma triggers	<b>MAKING SENSE OF ASTHMA</b>
<b>2. Sharing decisions</b>	2.1 Asking the parent for help with decision-making 2.2 Parent encourages child to make own decision but monitors behaviour 2.3 Parent and child do not always agree	<u>Decision-making is threaded throughout all initial themes</u>	- Child alerts parent/adult to symptoms - Parent encourages self-management - Any conflicting decisions with parent/adult - Parent action in response to symptoms - Parent challenges HCP's decisions/advice - Parent dominated decisions	<b>PARENT DECISION PREFERENCES</b>
<b>4. Parent control of the decisions</b>	4.1 Parent manages decisions relating to additional acute illness and more severe symptoms 4.2 Parent does not always agree with HCP'S decisions/advice 4.3 Observes for nocturnal symptoms 4.4 Parent overrides child's decision			
<b>3. Facilitators and barriers of child's self-management</b>	3.1 Child access to inhaler 3.2 Additional acute illness 3.3 Daily management 3.4 Parental	3.1 and 3.3 link to encouraging child in daily asthma management (1) 3.2 Additional acute illness	- Parent's confidence in child's ability to manage - Accessibility of inhaler - Parental absence/presence	<b>FACILITATORS AND BARRIERS OF CHILD'S SELF-MANAGEMENT</b>

	presence	require affirmation from parent on management decisions (4)	- Daily routine	
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Appendix 18: Example of child's  
drawing



**Appendix 19: Training**

<b>Date</b>	<b>Training</b>
4-5/9/14	UK Association of Chief Children's Nurses. Children's and Young People's Nursing International Conference, Jersey
27/9/13	Social Learning Theory, Manchester
23/9/13	Wordscope, Salford
5-6/6/13	Paediatric Nursing Association of Europe, Glasgow
6-7/3/13 & 8-9/05/12	NVivo, Salford
7/12/12	Celebrating Research Day, Salford
6/12/12	Dissemination and publication of research, Salford
11-12/9/12	Children and Young People International Conference, Leeds
16/05/12	Thinking and writing critically, Salford
16/05/12	Writing academically, Salford
29/03/12	Analysing Qualitative research (interviews), Salford
22/03/12	What to do with the literature when I have got it, Salford
15/03/12	Fieldwork in Qualitative research, Salford
01/03/12	Conducting Qualitative research (Interviews), Salford
29/02/12	e-seminar: an audience with Dr. S. Latimer on shared decision making within health care
08/01/12	Good Clinical Practice training, Online
20/10/11	How to write a PhD thesis, Salford
08/06/11	SPARC, Salford
28/04/11	Workshop on Ethics, Salford
12/04/11	Making the most of conferences, Salford
14/04/11	Ethical issues/Presentation, analysis and interpretation of qualitative data, Salford
10/03/11	Methods of data collection (1), Quantitative designs, Salford
10/03/11	Methods of data collection (2). Interviews and questionnaires, Salford
14/10/10	Searching for evidence/ Critical review, Salford
29/09/10	Getting by-getting Better: Introduction to learning and teaching for Graduate Teaching Assistants, Salford